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Distributed health literacy among people living with chronic conditions

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Abbreviations

DAWN	Diabetes, Attitudes, Wishes and Needs
DHL	Distributed Health Literacy
EU	European Union
IAPO	International Alliance of Patients' Organizations
ISHA-Q	Information and Support for Health Actions Questionnaire
HLQ	Health Literacy Questionnaire
METER	Medical Term Recognition Test
MINI	McGill Narrative Illness Interview
NVS	Newest Vital Sign
PCORI	Patient-Centered Outcomes Research Institute
UNESCO	United Nation Education, Science and Culture Organization
REALM	Rapid Estimates of Adult Literacy in Medicine
TOFHLA	Test of Functional Health Literacy in Adults
WHO	World Health Organization

Abstract

Background

Health literacy has become an important global issue in public health, permeating the literature and policy discourse internationally, as well as practices of health education and communication. Its importance as a social determinant of health is evident when limited individual health literacy negatively affects patients' ability to understand health information, the communication with physicians and compliance with recommendations and treatments. However, tangible and emotional support provided by health literacy mediators (e.g., caregivers, family, friends, health professionals involved in routine clinical care) is likely to improve self-care in chronic conditions, particularly among people with low health literacy.

Improvements on type 2 diabetes and asthma care might thus be achieved if scope on individual skills gets wider and in-depth knowledge about how health literacy is dispersed through a group is considered – distributed health literacy, by focusing on how patients draw on their social network for support with health-literacy related tasks. The development of broader measures of health literacy, with deeper understanding of the Distributed Health Literacy (DHL), may benefit from the analysis of illness narratives, in the sense that the point of view of lay experiences and 'patienthood' may help unpack a chronic illness self-management behavior since diagnosis. This approach represents the actual global strategy towards integrated people-centred health services, according to which co-production of knowledge, shared care and shared governance for health sustain the provision of tailored health services that aims to synchronize care both with and around the needs of service users, their families and the communities, meeting an individual's or group's specific characteristics and potential within the context of their lives.

Objectives

This thesis aims to explore the interactions between the demands of health systems and the skills of individuals, as well as the context and complexity of skills and support identified as necessary for patients with chronic conditions to be considered 'literate' in relation to their health.

To accomplish this general aim, three studies were performed, with the following specific objectives:

1) To explore how social networks and personal experiences are a portrait of the DHL, mapping out health literacy mediators (those who makes his/her literacy skills available to others for them to accomplish specific literacy purposes), and how they enable self-management skills in patients with i) type 2 diabetes **(Paper I)** and ii) asthma **(Paper II).**

2) To analyze the perceptions of patients with moderate to severe asthma about family influence in daily management of disease, taking into account the levels of literacy skills and the health information seeking behavior **(Paper III).**

3) To explore the perceptions on the constraining and facilitating factors to patient-centered communication in clinical encounters of patients with type 2 diabetes and the providers involved in their care **(Paper IV).**

Methods

This qualitative and cross-sectional study involved the conduction of 81 semi-structured interviews with three groups of participants. Between October 2014 and December 2015, an adapted version of the McGill Illness Narrative Interview (MINI) was applied to patients with asthma (n=20) and with type 2 diabetes (n=26) attending a primary care facility in the district of Porto. Data on sociodemographic characteristics, medical history, knowledge, self-management skills, navigation in health systems, social support and health mediators was collected in all interviews. From January 2012 to January 2013, an adapted version of the McGill Illness Narrative Interview was applied to patients with severe persistent asthma (n=35) at Hospital de São João, Immunoalergollogy Department. Finally, we conducted two focus group of health professionals (n=12) in 2012, in a research institute, and five focus groups of patients (n=33) in a health care center for the group without complications or hospital for the remaining four groups, between 2015 and 2016.

Data analysis was based in the principles of grounded theory, with constant comparison, contrast and synthesize and code data by theme and subsequently by thematic category. The procedure is case-based and process-tracing-oriented i.e., its basic analytical units are cases, corresponding to the illness experience narratives of subjects, which provide the materials for the exploration of the processes of interest. The criteria for closure of analysis were theoretical saturation.

Results

In the sample with patients with type 2 diabetes, three narratives emerged from the interviews: 1) narrative of minimization, revealing a low impact of diabetes in patients' lives and daily routines, resignation towards 'inevitable' consequences of the diagnosis, and a high dependence of a large network of health literacy mediators with complex interactions; 2) narrative of empathy, where patients tended to mention readjustments in their lives by following medical recommendations regarding medication without criticism and with few health literacy mediators; 3) narrative of disruption, with patients highlighting the huge impact of diabetes on their lives and their individual responsibility and autonomy on the management of diabetes and search for alternatives to medication, relying on a very restricted network of mediators. (**PAPER I**)

Two narratives emerged from the interviews to patients with asthma at the primary care center. Interviewees with a dense network of health literacy mediators enacted a narrative of minimization, characterized by low impact of asthma on patients' lives and dependence of general practitioners for instrumental support and of close family members with asthma to provide emotional and pragmatic

support with medication and alert to situations that might trigger an asthma attack. Interviewees who relied on a restricted network of core mediators belonging to formal sources of health services (clinical interaction or online) enacted a narrative of disruption, guided by the description of episodes of crisis as highly disruptive, experiencing difficulties in controlling crisis and feelings of stigma. This group also demonstrated a reactive approach to self-management skills and look for alternative and complementary solutions. (**PAPER II**)

In the study performed with patients with severe asthma, we identified two main profiles for information seeking: 1) Group 1, asthma is a 'family issue', 61% had more than 35 years old, and 43% have elementary education. Knowledge about asthma, and easy acceptance of diagnosis, is based upon the feeling of knowing well the condition, and on family contexts were asthma is a common condition. 2) Group 2, asthma is not a 'family issue', 91% have less than 34 years old, and 66% have higher education. Sharing decision-making was proved to be made within family contexts and suggests the shifting of responsibilities of patients and families in health care as they become more informed and engaged. (**PAPER III)**

In the focus groups with health professionals and patients, we concluded that patient-centered communication in type 2 diabetes is influenced by factors related with patient-provider relationship, disease and treatment-related behavior, and gathering and providing information. Patients focused on constraining and facilitating factors related with patient-provider relationship, while providers emphasized constraining factors when gathering and providing information and facilitating factors to effective communication regarding disease and treatment-related behavior. The patients and the providers interviewed for this study agreed that power imbalance, avoidance of reprehension by patients, patients' neglect of the disease, use of jargon, and insufficient competencies and consistency between providers were constraining factors to patient-centered communication in clinical encounters. (**PAPER IV**)

Conclusion

This qualitative and cross-sectional study provided evidence to sustain the importance of the DHL in the management of chronic conditions, with practical implications in the future development of integrated people-centred health services, namely the creation of hybrid spaces for dialogue between multiple mediators in each individual networks.

By exploring meanings given to diagnosis, assessing needs and vulnerabilities in access to health care, and identifying health mediators and the role of others in the management of disease, we reached into a deeper level of understanding about how contextual factors influence health literacy practices in the management of chronic diseases. To identify the diversity of roles performed by core health mediators in support for disease management is essential to clarify the boundaries of responsibility-shifting and to enable effective collaboration between health professionals, family/friends and media.

Additionally, the acknowledgement of the distributed nature of health literacy provides innovativeness

and complementary information about the influence of social networks to a more sustainable healthcare system, calling for a focus on DHL rather than just emphasizing individual health literacy. And the characterization of the awareness narratives - minimization, empathy and disruption - is an innovative and comprehensive way of understanding and identifying those practices across distinct profiles of patients. It is also a form of agency, meaning that people's reactions to illness are shaped by a variety of motivations, needs and emotions, showing that health literacy is not only about dealing with information on a cognitive level.

Resumo

Atualmente, a literacia em saúde é uma questão de saúde pública global, presente na literatura e nos discursos políticos internacionais, assim como nas iniciativas de educação para a saúde e comunicação. A sua importância enquanto determinante social de saúde manifesta-se na forma como a baixa literacia em saúde individual afeta negativamente a capacidade de compreender a informação sobre saúde, a comunicação com os médicos e a adesão aos tratamentos. No entanto, o suporte funcional e emocional dos mediadores da literacia em saúde (por exemplo, os cuidadores, a família, os amigos, ou os profissionais de saúde envolvidos nos cuidados de saúde mais regulares) contribui para melhorar os cuidados continuados em doenças crónicas, particularmente entre as pessoas com baixa literacia em saúde.

Os cuidados prestados no âmbito da diabetes e da asma poderão ser melhorados se o foco nas competências individuais se expandir, considerando o conhecimento aprofundado sobre a forma como a literacia em saúde se distribui em rede – a literacia em saúde distribuída (DHL), apreensível através da análise da forma como os doentes concretizam tarefas relacionadas com a literacia em saúde recorrendo ao suporte das suas redes sociais. O desenvolvimento de medidas mais abrangentes da literacia em saúde, compreendendo a sua distribuição na rede, pode beneficiar da análise das narrativas da doença, na medida em que a perspetiva do conhecimento leigo do doente e da experiência da vivência prolongada com uma doença reflete comportamentos de gestão da doença desde o diagnóstico. Esta abordagem entronca na atual estratégia global dos cuidados integrados de saúde centrados na pessoa, onde a co-produção de conhecimento, os cuidados partilhados e a governação para a saúde partilhada sustentam a provisão de serviços de saúde sincronizados em torno das necessidades dos seus utilizadores, das suas famílias e das comunidades, considerando as características e as potencialidades individuais e de grupo associadas aos contextos sociais de cada pessoa.

Objetivos

Pretende-se explorar as interações entre as exigências dos sistemas de saúde e as competências dos indivíduos ao analisar o contexto e a complexidade das competências e do suporte que as pessoas com doenças crónicas consideram necessárias para lidar com a sua saúde enquanto indivíduos "literados".

Na prossecução deste objetivo geral, desenvolveram-se três estudos com os seguintes objetivos específicos:

1) Explorar as formas como as redes de suporte e as experiências das pessoas são um reflexo da literacia em saúde distribuída dos indivíduos, mapeando o papel dos mediadores em saúde (aqueles que partilham a sua literacia com os outros de modo a que realizem determinada tarefa) enquanto facilitadores da gestão de uma doença crónica em doentes que vivem com i) diabetes tipo 2 **(Artigo I)** e ii) asma (**Artigo II**)**.**

2) Analisar as percepções de doentes com asma moderada a severa sobre a influência da família na gestão diária da doença, tendo em conta os níveis de literacia e as atitudes perante a procura de informação sobre saúde (**Artigo III**).

3) Explorar as percepções sobre os fatores constrangedores e facilitadores da comunicação centrada nos doentes de pessoas com diabetes tipo 2 e de profissionais de saúde envolvidos nos seus cuidados (**Artigo IV**).

Métodos

Este estudo qualitativo transversal envolveu a realização de 81 entrevistas semi-estruturadas a três grupos de participantes. Entre Outubro de 2014 e Dezembro de 2015, usou-se uma versão adaptada do McGill Illness Narrative Interview (MINI) para entrevistar pessoas com asma (n=20) e diabetes tipo 2 (n=26) num Centro de Saúde no distrito do Porto. Recolheram-se dados sobre as características sociodemográficas, o historial médico, o conhecimento sobre a respetiva doença e competências de gestão, navegação nos serviços, suporte social e mediadores de saúde. De Janeiro de 2012 a Janeiro de 2013, o mesmo guião foi aplicado a pessoas com asma severa persistente (n=35), no Departamento de Imunoalergologia do Hospital de São João. Por último, realizaram-se dois grupos focais com profissionais de saúde (n=12) em 2012, num instituto de investigação, e cinco grupos focais com pessoas com diabetes tipo 2 (n=33) entre 2015 e 2016, num centro de saúde a um grupo sem complicações e num hospital aos restantes quatro grupos focais .

A análise dos dados foi feita com base nos princípios da *Grounded Theory* (teoria enraizada nos dados), envolvendo constante comparação, contraste e resumo dos dados codificados por temas, e subsequente categorização temática. Desenvolveu-se um processo de identificação de casos, ou seja, uma análise focada em cada um dos casos, que correspondem às experiências das narrativas da doença de cada indivíduo, o que proporciona materiais analíticos para explorar os processos de interesse. Usou-se o ponto de saturação como critério para finalizar a análise dos casos.

Resultados

No grupo de participantes com diabetes tipo 2, emergiram três narrativas: 1) narrativa da minimização, revelando um baixo impacto da diabetes no dia-a-dia dos doentes, assim como uma certa resignação relativamente a consequências 'inevitáveis' de um diagnóstico de diabetes e uma grande dependência de uma rede densa de mediadores com interações complexas; 2) narrativa da empatia, cujos participantes referiram reajustes feitos no dia-a-dia de modo a seguirem acriticamente as recomendações médicas, sobretudo em relação à medicação, contando com uma rede que envolve menos mediadores que o grupo da minimização; 3) narrativa da disrupção, onde o diagnóstico da diabetes teve um enorme impacto nas vidas dos participantes, reportando uma assumida responsabilidade individual e autonomia na gestão da

diabetes e na procura por soluções alternativas à medicação, dependendo de uma rede muito restrita de mediadores. **(ARTIGO I)**

Duas narrativas emergiram das entrevistas aos participantes com asma no Centro de Saúde. Os entrevistados com uma rede densa de mediadores de saúde acionaram uma narrativa de minimização, caracterizada por um baixo impacto da asma nas suas vidas e uma grande dependência do médico de família sobretudo em termos de suporte instrumental; e dependência dos familiares mais próximos com asma, em termos de suporte emocional e pragmático, nomeadamente ajuda com a medicação e alerta para situações que possam despoletar uma crise de asma. Os participantes que reportaram uma rede restrita de mediadores, sobretudo pertencentes à rede formal de serviços de saúde (na interação clínica ou serviços de apoio à saúde online) apresentaram uma narrativa de disrupção, vivenciando dificuldades no controlo da asma em momentos de crise e sentimentos de estigma. Este grupo reportou uma atitude reativa no uso das competências de gestão da doença, procurando alternativas e soluções complementares quando vivenciam crises. (**ARTIGO II)**

No estudo com os doentes com asma severa, foram identificados dois grupos: 1) Grupo 1, com asma na família, 61% tinham mais do que 35 anos, 43% tinham apenas o ensino básico. O conhecimento sobre asma e a aceitação da doença mostraram depender da familiaridade e da vivência com a doença, uma vez que a asma faz parte do contexto familiar. 2) Grupo 2, sem asma na família, 91% tinham menos de 34 anos, e 66% tinham formação superior, demonstrando uma atitude de negação da condição após o diagnóstico, sustentada pelo facto de mais ninguém da família sofrer da mesma condição de saúde. A partilha da decisão sobre saúde foi feita no contexto familiar, sugerindo a existência de uma transferência de responsabilidades para o doente e famílias nos cuidados de saúde, quanto mais informados e motivados estes se encontrarem. (**ARTIGO III)**

Nos grupos focais com os profissionais e os doentes, concluiu-se que a comunicação centrada nas pessoas com diabetes tipo 2 é influenciada por fatores associados com a relação doente-profissional de saúde, com a doença e o comportamento face à gestão da doença, e com a forma como os doentes procuram e recolhem informação. Enquanto os doentes focaram as barreiras e facilitadores na relação do doente com o profissional de saúde, os profissionais colocaram as barreiras mais ao nível da forma como os doentes procuram e recolhem a informação e destacaram os facilitadores relacionados com os comportamentos de gestão da doença por parte do doente. Doentes e profissionais concordaram que o '*power imbalance'*, o evitar ouvir uma repreensão dos médicos, o ignorar da doença, o uso de termos médicos, e a insuficiência de competências e de consistência entre os profissionais são barreiras na comunicação centrada no doente nos encontros clínicos. **(ARTIGO IV)**

Conclusão

Este estudo qualitativo observacional concluiu que a literacia em saúde distribuída é relevante na gestão de doenças crónicas, em termos práticos e relacionais, o que tem implicações no desenvolvimento de serviços de saúde integrados e centrados nas pessoas, nomeadamente na necessidade de criação de espaços híbridos de diálogo entre os vários mediadores de cada rede individual.

Ao explorar os significados atribuídos ao diagnóstico, ao avaliar as necessidades e vulnerabilidades no acesso aos cuidados de saúde, e ao identificar a rede de mediadores de saúde e o respetivo papel na gestão da doença, este estudo contribuiu para aprofundar o nível de conhecimento e a compreensão sobre os fatores contextuais que influenciam as práticas de saúde na gestão das doenças crónicas. Identificar os diferentes papéis dos mediadores no suporte à gestão da doença é essencial para clarificar os limites da transferência de responsabilidades, de modo a permitir uma colaboração mais eficaz entre os profissionais de saúde, família/amigos e media.

Adicionalmente, o reconhecimento da literacia em saúde distribuída é inovador e complementa a informação sobre a influência das redes sociais para um sistema de saúde mais sustentável, salientando a necessidade de um foco maior na literacia distribuída em vez de unicamente centrada nas capacidades individuais. A caracterização das narrativas – minimização, empatia e disrupção – apresenta uma perspectiva renovada que ajuda à compreensão e identificação de práticas sobre saúde de acordo com os diferentes tipos de doentes, a partir de diferentes formas de reação ao diagnóstico, as quais são influenciadas por motivações, necessidades e emoções, mostrando que a literacia em saúde não reside unicamente na forma como se lida com a informação a nível cognitivo.

1. Introduction

1.1 From individual to distributed health literacy

Health literacy has become an important global issue in health, permeating the literature and the policy discourse internationally. Over the last decade, the interest in health literacy has proliferated worldwide [1], reflecting the investment of the UNESCO through the international plan of action - United Nations in the Literacy Decade (2003-2012) and the proliferation of national campaigns, graduate programs, philanthropic projects, and job offers related to health literacy and health communication [2]. This illustrates how health literacy has become a touchstone for public health initiatives, with important concern in the political and research agenda. The inclusion of health literacy both in World Health Organization (WHO) publications [3], and European policy documents [4-6] and in national health agendas in high income countries, has been responsible for an increase of projects of health literacy worldwide.

These achievements contributed to the quite recent emphasis on the problem of low health literacy, that has been highlighted by researchers, politics and health professionals as a pressing international priority, and as an opportunity to improve health outcomes and reduce health inequalities [7,8]. Many studies demonstrated associations between low health literacy levels and health, namely poor health-related knowledge [8], the increased hospital admissions and readmissions [9-11]; less participation in preventive activities [11-15]**;** higher prevalence of health risk factors [16,17]; poorer disease outcomes [18]; lower functional status [19]; and increased mortality [20-22]. Contributions from research are rapidly increasing understanding of the potential that optimizing health literacy can have in improving health and well-being [23,24]. In addition, they also sustain that health literacy might function as a stronger predictor of an individual's health status rather than income, employment status, education level and racial or ethnic group [25].

These results are largely based on the assessment of individual health literacy skills. The concept of health literacy appeared in the literature in 1974, first introduced by Simonds [26], in a discussion of health education as a policy issue affecting the health system, intending to reflect the intersection of the fields of literacy and health. Health literacy begin as a simple description of the individual ability to perform related tasks that are reading and numeric skills [26]. Two decades later, the World Health Organization (1998) describes health literacy as "*the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health*" [27]. Thus, while deriving from the study of reading and numerical skills, the concept of health literacy has expanded in meaning to include decision-making [28], information-seeking [29], and evolved so that the concept commonly refers to people's capacity to obtain, process and understand basic (written or oral) health information and services needed to make critical judgements, to communicate and to negotiate health decisions [30-32] not only in health-related settings, but also covering the demands of health systems [6,33,34]. Thus, taking into account the social, personal, and cognitive skills that are imperative to function in the health-system - now diffused to the realm of culture, context, and language [28,31,35].

Studies in the field of health literacy focus predominantly on the development and administration of quantitative instruments to assess individual skills. The typical instruments used to measure health literacy epitomize a knowledge that is almost exclusively defined by the biomedical canon, and put emphasis on the individuals' ability to understand medical terms and baseline information related to medical prescriptions and exams, prevention of diseases and self-care [27]. Popular instruments such as the Newest Vital Sign (NVS) [36]; the Rapid Estimates of Adult Literacy in Medicine (REALM) [37]; the Medical Term Recognition Test (METER) [38]; the Test of Functional Health Literacy in Adults (TOFHLA) [39], are the most commonly used. The NVS [36] uses a scenario (the ice cream nutrition label) and 6 questions based on the ability to read and apply information from a nutrition label and can be administered in approximatedly 3 minutes. The REALM can be administered in one to two minutes and provides reading grade estimates for patients who read below a ninth-grade level - patients are required to read a list of words aloud, and a practitioner must be present to score pronunciation accuracy. Like the REALM, the METER only takes two minutes to administer, and the patient is given a list of items and is simply asked to check off those he/she recognize as actual words. TOFHLA administration is longer (about 22 minutes to complete) and involves written tests that are self-administered: a shorter version of TOFHLA was created and requires around 7 minutes to complete - is equally focused on reading and numerical comprehension in a structured questionnaire.

Although measures of health literacy have traditionally focused on a limited range of health-related reading and numeracy skills [40], recent developments have increased their capacity to assess needs across a more extensive set of dimensions of health literacy. Kickbusch et al.[41] encourages an understanding of health literacy as dynamic, active and empowering, an important life skill required 'to navigate modern society' and to guide the choices in everyday life influencing health and well-being. This proposal is much like Nutbeam's [31] original definition, where he states that the cognitive and social skills are determinants not only to an individual's knowledge, but also to the motivation and the ability to access, understand and use information in ways that support and uphold good health [27]. In 2012, a systematic review developed by Sorensen [34] and colleagues, identifies 17 definitions of health literacy from 1998 to 2009 and proposes a new integrated definition. This '*new all inclusive*' comprehensive definition encompasses more deeply the public health perspective: "health literacy is linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during life course" [34]. Authors combine an integrated conceptual model of health literacy including 12 dimensions, with competencies related to accessing, understanding, appraising and applying health information in the domains of healthcare, disease prevention and health promotion (Figure 1).

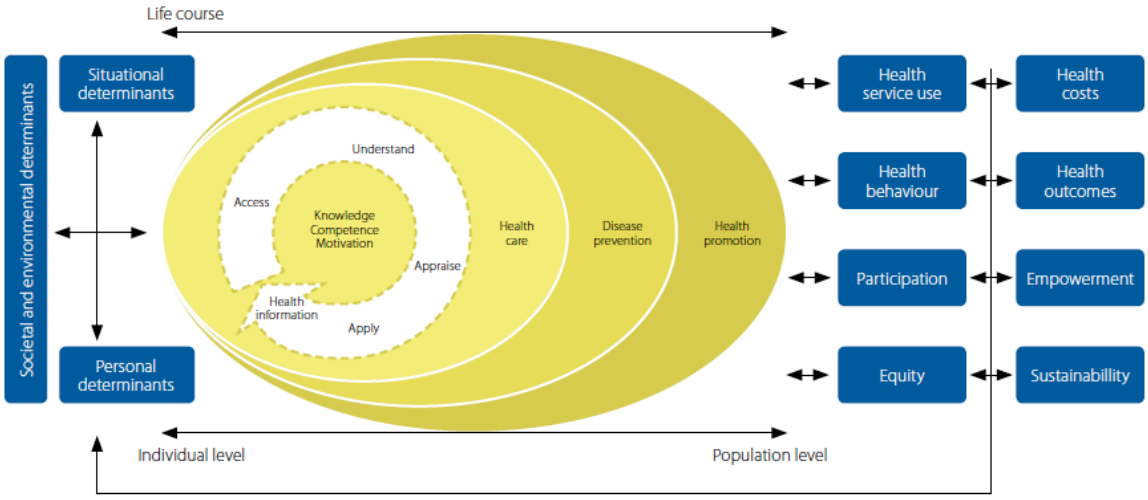

Figure 1. Conceptual model of health literacy of the European Health Literacy Survey [34]

New tools for assessing broader dimensions of health literacy were then developed, as for example the Information and Support for Health Actions Questionnaire (ISHA-Q)[42,43] and the Health Literacy Questionnaire (HLQ) [43]. Both questionnaires are outcomes of the OPHELIA Approach [43], which involves the collaboration of a wide range of community members, community leaders and workers to develop health literacy interventions that are based on needs identified within a community. It comprises several projects that seek to "improve health and equity by increasing the availability and accessibility of health information and services in locally-appropriate ways" [43]. ISHA-Q is a multidimensional tool that aims to allow the development of 'fit-for-purpose' response strategies for optimizing opportunities to improve equity in health outcomes and access to care. It was developed to measure health literacy in low and middle income settings, and cultures where decision making about health frequently happens as a shared activity of family or peer groups. The HLQ, more driven to organizations and professionals, measures nine domains of health literacy, assessing needs and organizational structures. Whilst these advances in measurement create the potential for providers, organizations and governments to develop fit-for-purposed health literacy responses, measurement of health literacy has proved complex. Both instruments can be self-administered (7 to 30 minutes) or orally administered by interviewer (20 to 45 minutes). Nonetheless, new measures still do not capture the broader perspective of several dimensions of health literacy, as for instance, communication between patients and health professionals and the role of others in the health literacy of individuals and in health-related decision making.

Literacy is constructed and acquired through interpersonal interaction in particular environments where skills and modes of thinking may be differently celebrated and promoted. Kickbusch [41] (2006) states 'health is everywhere': health magazines, the Internet, television and radio, and even social and interpersonal relationships may influence the context in which information is accessed. An individual's

personal, cognitive and social skills play a crucial role in health literacy but are subject to influences well outside of the control of health professionals and the health system [32]. As a consequence, more and more scholars are encouraging an understanding of health literacy as a 'situated practice' and a shared resource commonly acquired jointly by groups of people [44]. When health literacy researchers have introduced a critical new variable, health literacy skills, that can be measured and compared, other key strategic variables, such as literacy as shared practice, skills of communicators or complexity of health systems, have not been considered [33,44,45-47]. Since then, academics in the field of health literacy are looking beyond an individual capacity and consider the input of others both on decision-making and on literacy capabilities [48]. In 2015, Edwards et al.[49] proposed the concept of DHL, an adaptation of Wagner et al. [50] term "*distributed literacy*". Distributed health literacy refers to the way in which health literacy is distributed throughout a group of individuals or a community [49]: "*Health literacy is distributed through family and social networks. It allows people living with a long-term condition to draw on their social network for support with health literacy-related tasks such as managing their condition, interacting with health professionals and making decisions about their health*." The concept envisions health literacy as a shared resource through an individual's social network, and an 'asset' that can be individual or can also be found throughout groups of people, such as in families, support and community groups [51].

1.2. Health literacy mediators

In 1995, literacy mediators were firstly described by Baynham [52] as '*a person who makes his or her literacy skills available to others, on a formal or informal basis, for them to accomplish specific literacy purposes'*. Following Bayhnam's [52] definition of '*literacy mediators'*, Edwards describes individuals who share their health literacy skills as '*health literacy mediators'* [49] - skills that consider the contextual nature of reading and writing in health care settings and how patients make sense of their experience and the resources draw on, for example. Many people experience situations where health-related decisions are strongly influenced by family members, peers or community leaders, health professionals and media [49,53-55].' It also means that discussions about health in communities and social networks influence pathways for people to find, interpret and apply health information, and to share health information and experiences influence how people think and act in relation to their health and reflect an individual's social support [56].

In line with these conceptions, Lee et al. [57] systematic review about the interrelationships between health literacy, social support and health status, concluded that '*the positive resources and support in individuals' social networks can improve their ability to acquire and understand health information and to negotiate the healthcare system'*. It also suggests that positive social support may protect persons with limited health literacy from potential adverse health outcomes, but negative or harmful interactions with social network members may exacerbate these potentially adverse health outcomes [57]. In fact, there is evidence that some patients with poor results on individual health literacy still keep diabetes under control [58,59]. They may be able to manage their condition without fully understanding it, or rely on significant others - health literacy mediators [49,52]. Several individuals may each possess only some aspects of literacy, and by merging strengths, they may function as more entirely literate persons – at the end, there's a number of individuals that may contribute to different aspects of one literacy action in each social network [50]. In spite of these developments, by treating health literacy as an individual characteristic, previous literature has often overlooked the potential for social networks to minimize the adverse effects of limited health literacy on access to care while helping to deal with the demands of health systems and health outcomes [49]. A deeper understanding of health literacy mediators can guide the health system of public health practitioners, care providers, insurers, and community agencies toward adopting definitions and policies that resolve incompatibilities between the needs of individuals and the demands of health systems [33].

Back in 1982, pioneering case studies in India, highlighted the influence of communities on health practices, showing that sharing information and experiences among mothers living in the same village increased the probability of immunizing their children, with this factor being stronger correlated with childhood immunization rates rather than the individual literacy level of mothers [60]. Social life occurs in circumstances where health-related decisions are not made just by individuals but are powerfully influenced by family members, peers or community leaders, media, health professionals and health organizations [43,55]. It is therefore critical for health literacy interventions in communities to understand

how dialogues about health that occur within families, among friends and peers, and other social networks, influence how people think about and take decisions in relation to their health and how they find, apply and interpret health information.

Moreover, previous literature shows that literacy is not only shared but is also 'situated' [61] – located in particular times and places. For instance, Rapley [48] explored the role of an individual's social network in the shared decision-making process, one critical dimension of health literacy. To expand the individual concept of decision making, Rapley analyzes a range of studies of medical interaction, knowledge, context and technology, and describes two sides of the distributed nature of health decision-making process, suggesting that: on one hand, it is hardly just a 'solo cognitive' experience and, on the other, it is usually distributed 'over' people. The author considers that decisions are an 'ongoing event' that develops over a number of interactions with others and are distributed in social networks of individuals. Knowledge might be distributed over medical encounters between clinicians and patients and also among patient's significant others, through an accumulation of series of past encounters [48]. Following Rapley's perspective, Papen's [44] considers literacy mediators a resource available within an individual's health network and extend and enhance an individual's health literacy. A Canadian study [62] with cancer patients specifically examined the role of significant others – that is, the social network, family members and friends – in decision making about complementary and alternative medicine, and concluded that significant others are involved in the process of decision making, by encouraging, collaborating, persuading and making the decision.

A couple of studies have explored the role of informal social ties (specifically, family) in the pathways between health literacy and chronic conditions, such as type 2 diabetes, asthma and heart failure [63-68]. Literature suggests that some chronic conditions, such as asthma and type 2 diabetes, are more 'family issue' than others because management occurs very typically in the context of family routines: (i) family emotional characteristics and asthma management behaviors account for key influences on paediatric onset and outcomes [68]; ii) family members are claimed as an indispensable source of support for self-care among adults with type 2 diabetes [69]; (iii) family members involvement in diabetes management may help some patients overcome health literacy-related barriers, potentially explaining inconsistent associations between limited health literacy and worse glycemic control [58]; (iv) informal social support showed significant indirect effects on glycemic control mediated by access to care – higher social support was associated with higher self-care, access to care and processes of care [70]; (v) higher health literacy was associated with less informal social support for diet [71]. A qualitative study observed that patients naturally mentioned family members' behaviours helping in tasks such as ordering and picking up prescription refills, reminding patients to take medications, or even carrying healthy snacks or medications with them for the patient, exercising with the patient, or purchasing and preparing healthy foods [72].

Notwithstanding, patients report that their family members perform both supportive and obstructive behaviors [75]. Mayberry [73] concluded that involving family members in adults' self-care without teaching

them to avoid obstructive behaviors may be particularly harmful for patients with limited health literacy. Adults with limited health literacy are especially vulnerable to the harmful aspects of family involvement in their diabetes management [74]. The interpersonal relationships, either those created through informal social ties such as friends/family or community organizations or those with healthcare providers, may also be sources of health information, and provide different types of support [75,76]. Social networks describe the patterns through which individuals are connected to one another through social ties [77]. Back in 1969, Mitchell [78] has defined social network as a '*specific set of linkages among a defined set of persons, with the additional property that the characteristics of these linkages as a whole be used to interpret the social behavior of the person involved*". Social networks are defined as a people-centered characteristic and can be categorized along three dimensions: 1. Structural – refers to the links in the whole network; 2. Interactional – refers to the nature of the connections; and 3. Functional – are the functions provided by the network [78]. Structural characteristics are analyzed by their range (size of the contacts) and density (the links that could exist and do exist). Interactional characteristics are defined by the i) *Content*: the meanings attributed to the relationships; ii) *Directedness*: the reciprocity in a relationship; iii) *Durability*: the length of time people in a network know each other; iv) *Intensity*: the emotional attachment between members of a network; v) *Frequency*: the amount of interactions; vi) *Dispersion*: boundedness, the ease with someone can make contact; and vii) *Homogeneity*: similar social attributes [79,78]. In terms of functional characteristics, different kinds of support are identified: affective support (provision of moral support, caring), instrumental support (provision of tangible aid and services), cognitive support (access to diverse information) and there's also the maintenance of social identity (validation of a shared world) and social outreach (access to social contacts) [79,78].

Identified the mediators and types of support, it is critical to analyze the unmet needs from patients, as for example, core areas of self-management of long-term conditions, namely, decision making, or even, resource utilization and development of effective partnership and communication with healthcare providers [80,81]. At the center of the relationship between clinicians and patients is communication [82]. Poor communication are one of the most common patient complaints and contribute to patient harm [83,84]. Studies highlighted the need for clear communication and health literacy curricula for health professionals [85-87], also because health professionals have reported feeling difficulties to communicate with people with low health literacy [88]. For example, how does health professionals build their own knowledge, if based on the 'cookbook' health guidelines or/and if it is influenced by 'knowledge in practice'. Gabbay and Le May [89] use the notion of 'communities of practice' - it is informal knowledge and is everywhere, a place for the *creation* of knowledge through mutual engagement and shared experiences - to explore how primary care clinicians derive individual and collective discussions about best practice and how these interact. In 1998, 'communities of practice' were considered by Wenger [90] as a reflect of learning and a participation in the social world. This raises an important conception of how knowledge and practice are framed, and how does it influences the process of decision making [48].

Currently, it is supported that a broader understanding of health literacy can facilitate patient engagement in self-care, considering that it has a range of two-way interactions between patients and their significant ones, such as family members and caregivers, and the members of the healthcare system [91]. This renew approach is based on a social ecological model (Figure 2), according to which individuals are influenced at multiple levels by macro-policies, communities, organizations and interpersonal dimensions [92]. It includes micro and macro dimensions that might influence health literacy and patient engagement beyond the individual scope and considering other subjects such as the delivery of health information, the materials and tools provided to the public, the communication skills of public health and healthcare professionals, the attributes of health-related institutions, and the health policies that influence the systems in which they work [93].

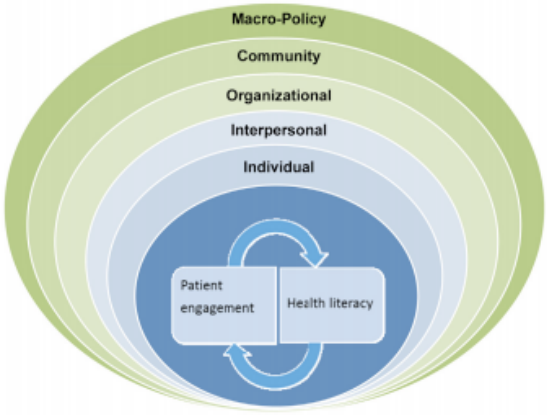

Figure 2. Integrated relationship between health literacy and patient engagement [93] **.**

Creating supportive environments for people to access and seek to understand health information, or to interact with health professionals, moving through their community and organizational contexts, is one of the purposes of this model [93]. Yet, there is a paucity of high-quality research on bringing people together by sharing knowledge, facilitating learning and supporting decision-making [49]. Despite these calls to change the focus of health literacy research from examining individual skills and deficits to more comprehensive and broader perspectives that include not only individuals and populations but also health professionals and health systems [94], there have been no systematic attempts to enlarge the conceptualization of health literacy and to integrate effective advances to address low health literacy and increase patient engagement [93]. In order for this to happen, the field of health literacy claims not only the above-mentioned paradigm shift from a focus on individuals' skills to a broader perspective, but calls more attention to the communication skills of health professionals, and the types of support provided by health networks of each individual.

1.3. A Narrative-Oriented Approach

The study of the DHL calls for a methodological approach capable to capture those broader dimensions: a narrative-oriented approach. Narrative medicine can be applied in theory, research and practice, whether if it is used as a specific therapeutic tool, a special form of patient-provider communication or a qualitative research tool [95]. People-centred care starts with the person's subjective experience of his or her health/illness and its impact on daily life – the narrative of the patient [96-98]. A narrative is defined as 'a spoken or written account of connected events' and has always been a fundamental part of medicine [99]. It is claimed that an efficient practice of medicine requires narrative competence, which is, the capacity to acknowledge, engage, understand, and act on the stories of others [100]. The term "narrative medicine" comes from Rita Charon [101], an internist and scholar, who uses it, in 2001, to describe an advance to medicine that uses narrative skills to enhance understandings of illness, arguing that through reading stories in clinical settings and through theory, medicine narrative prepares clinicians to receive patients' stories through practice. Charon advocates that by improving narrative skills the physician is qualified to practice medicine with 'empathy, reflection, professionalism, and trustworthiness' [96]. Based on models of person-centred care, medicine narrative provides the means to understand the personal connections between patient and physician, through an approach to improve attentive and emphatic care [100].

The importance of narrative is recognized both by health and social sciences (e.g. law, history, sociology, anthropology, and nursing) [102-105], rooted on interpretative approaches from medical anthropology and sociology of health. In the 1960s, Balint [106] argued the importance of analyzing the patient's unique psychological and social context, in the sense that stories about patients provide insight into respective experience of being ill or caring for the ill and can promote mutual understanding between patient and health professionals. Arthur Kleinman [107], in his book *The illness Narratives: Suffering, Healing, and the Human Condition*, comprised twenty years of clinical research in chronic conditions, documenting a series of 'illnesses narratives'. Kleinman's illness narratives made a convincing example for the need to meet the breach between patient and clinician. He encourages a 'meaning-centered medicine' where clinicians consider not only patient biological claims but simultaneously establish an empathic relation with the suffering of the patient, trying to minimize major psychosocial stresses that could harm illness management [107]. Following Kleinman's insights, Katy Charmaz [108], in her book *Good Days, Bad Days: The self in chronic illness and time*, used qualitative methods to explore how chronic illness affect not only bodies but also redesign people's sense of illness meaning and time. Arthur Frank [109], in his book *Wounded Storyteller: Body, Illness and Ethics*, used his own experience with both cancer and heart attack, and did qualitative research on a range of illness narratives. He compares the diagnosis of any illness to the loss of the 'previous life map that guided the ill person's life'. As a result of this, the sick person has to learn to think in a different way, and storytelling/narratives are part of the learning process: "they need to tell their stories in order to construct new maps and new perceptions of their relationships to the world" [110]. Howard Brody [111], a physician and scholar, calls the "stories of sickness", putting back to medicine its

humane side, with his understanding of *storytelling as healing*. For Brody, a good story is a central feature of what is known for the "placebo effect" because the effects might be therapeutic along with an "explanation consistent with the person's worldview, a connection to a community of practitioners and concerned others who share this worldview, and a sense of mastery and control over the experience" [111].

Ekman et al. [112] consider that narratives are the starting point for building a collaborative relationship between the health professionals and the patients. In order to encourage and empower patients to actively take part in finding solutions for their health problems, Ekman categorizes three dimensions of people-centred care that involve narratives: firstly, initiating the partnership (patient-provider) with patients' narratives; secondly, working the partnership through shared decision making; and finally, to protect the partnership through documenting the narrative. Greenhalgh [97] highlighted the relevance of studying narratives in different dimensions: i) in medical consultations, they encourage empathy and promote understanding between the clinician and patient, allowing, at the same time, the construction of meaning; ii) in therapeutic process, narratives are therapeutic or palliative and encourage a holistic approach to management; iii) in education of patients and health professionals, they encourage reflection, are memorable and grounded in experience; and iv) in research, narratives help to set a patient-centred agenda and may generate new hypotheses.

In sum, a narrative-oriented approach may expand and enrich the research agenda, by providing meaning, context, and perspective for the patient's quandary and defining "how, why, and in what way he or she is ill" [97]. Connecting patients, health care mediators and researchers would not only improve the communication between these networks, but also trigger social innovations of care models in which new ways of interacting and deciding improve the quality and efficiency of the health organizations [112]. Thus, a renewed focus on understanding patients' experiences is now being observed among academics and practitioners [113,114].

1.4. Integrated People-Centred Care in Chronic Conditions

In the paternalistic model of healthcare delivery, the professional's role is one of authority and of employing technical knowledge while having the commitment to keep emotional detachment from patients' experiences [115]. This perspective brings us the social construction of the sick role, as Parsons [116] described it, is a 'social role' characterized by duties and obligations of the parties to the doctor-patient relationship that "it is shaped by the society to which parties belong" [117,118]. The 'sick person' has the responsibility to try to get well - always focused in the resolution of the episode of illness and return to 'normality' [115,118]. It is expected the 'sick person' to assume his/her condition of disabled, which releases him/her from the normal social duties, and to cooperate fully with the doctor, while doctors are expected to apply their specialized knowledge and skills for the benefit of the patient [115]. Patients are considered powerless and passive relying in doctors' expert knowledge, who are in total control of the situation and have to make the decisions for the patient [119].

By contrast, Byrne and Long [120] defined, in 1976, patient-centredness as a style of doctor-patient interaction in which the main components to take into account were how medical authority was shared between doctors and patients and how patients were involved in consultations. In 2000, Mead and Bower [121] referred to these interactions of sharing power and responsibility between doctor and patient as "therapeutic alliance", in which the patient involvement in decision-making about their treatments became central to the provision of health care.

The 21st century is pictured as the century of people-centred care, especially in the care of the chronically ill [122]. Because health systems have become overly biometrics-oriented and doctor-dominated, the WHO advocates putting patients at the center of health care addressing people-centred care is a key dimension of health care quality [123]. The concept is not new, having its roots in humanistic psychology through the work of, for example, Rogers [124] and Heron [125]. It was initially used in the field of elderly care, particularly among vulnerable people. Today, more and more health professionals, policy makers, and managers consider that patients and health systems could benefit from a people-centred approach to care in which the patient is no longer the inactive target of a medical intervention, but is instead involved in his or her health care [112]. There are 'multiple definitions and descriptions' and different accounts of what this means, the term is often used interchangeably with '*patient*-centred care' (health settings), '*client*-centred care' (corporate world) and '*consumer*-centred care' (public services) [126], all expressing the idea of person-centredness [127,128].

Currently, people-centred care is widely accepted as the philosophy and practice that reinforces quality care, and it has become an important global issue in health research and political agenda. More recently, studies envision the importance of people-centredness in an integrated health care perspective [129,130]. Evidence suggests that people-centred and integrated services are essential components of building universal health coverage and can improve health status [130].

The European Union debated on the European Work Programme for the H2020´s Societal Challenge of Health the need for more integrated, sustainable and citizen-centred care, calling for action-oriented research to develop new, or improve the existent, models for integrated health systems in order to make them more people-centred [131]. In 2015, the WHO [132] provides a report presenting evidence about people-centred and integrated health services, proposing five strategic directions, describing a range of potential interventions and strategies that exist within each, and the strength of evidence for positive benefits. The first strategy is *empowering and engaging people*, not only individuals, but also carers and families. Evidence shows the impact on a range of outcomes, including health literacy, patient experience, service utilization cost, and health outcomes [133]. The second strategy is *strengthening governance and accountability*, this includes methods such as: 1. Engaging communities in shaping services through strategies such as decentralization; 2. Community consultations; 3. Providing systems to listen to people's views through survey based methods of report cards; and 4. Preserving rights and responsibilities through patient charters and legislation. The third strategy is *reorienting the model of care*, communities, health organizations and countries should consider what type of services should be proposed, where and how they should be delivered, and to whom they should be provided. The fourth strategy is *coordinating services,* the primary goal is to deliver quality health services through better organization of care activities involving individuals and all the health care providers they encounter. Finally, the fifth strategy proposed is *creating and enabling environment*, in order to facilitate the first four strategic directions towards achieving people-centred and integrated services. In 2015, the WHO draws a new report calling for a paradigm shift to answer the challenges faced by the health systems worldwide, incorporating integrated people-centred care and drawing attention to the way health services are funded, managed and delivered [133].

Literature discusses the "polymorphous nature of integrated care itself" and as a result there is no unifying definition of integrated care [133]. However, most overlapping definitions share the notion that, similar to people-centred care, it should go beyond an approach that only meets epidemiological population profiles to one that contemplates the holistic needs of the individuals and purposes of the communities [133,134]. According to Shaw et al. [135], integrated care implies that the patient's perspectives are at the heart of any discussion. It requires '*the patient perspective as the organizing principle of service delivery*' [136]. A health system-based definition used by the WHO describes integrated health care delivery as "*an approach to strengthen people-centred health systems through the promotion of the comprehensive delivery of quality services across the life-course, designed according to the multidimensional needs of the population and the individual and delivered by a coordinated multidisciplinary team of providers working across settings and levels of care. It should be effectively managed to ensure optimal outcomes and the appropriate use of resources based on the best available evidence, with feedback loops to continuously improve performance and to tackle upstream causes of ill health and to promote well-being through intersectoral and multisectoral actions*" [137]. Integrated care is seen as an important framework to develop better and more cost-effective health systems. In practice, it

denotes an approach to the provision of services that seeks to organize care both with and around the needs of service users - it is an organizing principle for care delivery aiming to achieve improved patient care through better organization of care [134].

However, health systems and health care institutions are among the most complex and interdependent entities known to society and optimal organization is quite difficult to achieve [138]. Without integration and organization at various levels (as for example, primary care with long-term care and patients' health literacy), several aspects of health care performance suffer: patients get lost, needed services fail to be provided, or are delayed, quality and patient satisfaction decline, and the potential for cost-effectiveness reduce [139].

This is particularly critical for patients with chronic conditions if considered that they are long-term users of the healthcare system. It is not surprising that self-management care planning considers integrated people-centred care a fundamental principle for chronic care. Long term conditions are ongoing and need to be manage for life, this generally implies that the quality of life of the patient, his work and family may be affected [140,141]. Care services should adapt to meet individual's characteristics and potential within the context of their lives, as recognized in the co-production of health (Figure 3). Nowadays, the focus in consultations for chronic conditions is changing to emphasize self-management through patient involvement [142]. Strategies can vary from coproducing care plans with service users to educational programs that support health literacy and self-care [143]. The way patient is conceptualized is also changing, with his/her role moving from one of passive recipient of care to one of "co-producer of health", being an active subject in self-care management and in the governance and improvement of health services [121,144,145]. Co-production is very customized to the unique needs of patients, under the assumption that they are active recipients of care and it has positive impact in the management of long term conditions [146].

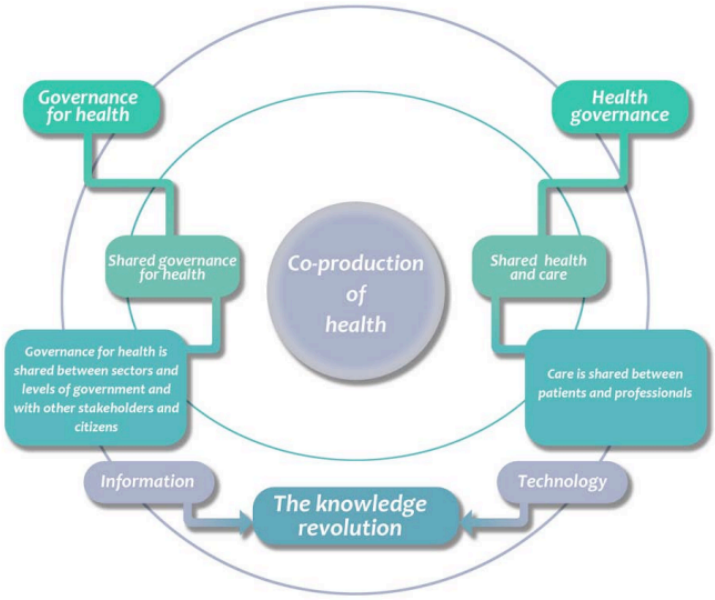

Figure 3. Structure of co-production of health [143]

Chronic diseases pose a considerable burden for national economies, with some studies estimating the related costs at up to 7% of a country's gross domestic product [147]. Aiming to reduce the burden of chronic conditions, both the Chronic Care Model (CCM) and the World Health Organization's Innovative Care for Chronic Conditions highlight the need for patient-centered care and self-management support [148 149]. The CCM [122] was an outcome of an extensive systematic literature review that documented factors and components with positive impact on patient outcomes, quality of care and cost savings. It proposes a shift from acute, episodic and reactive care towards care that is longitudinal, preventative, community-based and integrated, and one of the main tasks for health services should be to support self-management [150]. People suffering from chronic conditions have complex and continued needs (medical, physical, psychological and social), experience difficulties in everyday living, require a mix of services delivered sequentially or simultaneously by multiple providers and receive care both in home, community and institutional settings [138].

This thesis focuses on two increasingly prevalent chronic conditions, worldwide and in Portugal - asthma and type 2 diabetes. Although these conditions display different medical regimens recommendations, both have the most robust evidence base for the effectiveness of implementing supported self-management, as for example, patients and peer support groups [151], and family support [63-66]. At the same time, these conditions show that the 'course of the disease may be labile' and implies significant participant by informed patients [152] and poses multiple challenges to health systems [153].

Nearly 422 million adults worldwide had diabetes in 2014, and this number is estimated to rise to 700 million people by 2025 [154]. In 2015, Portugal was estimated to have the highest age-adjusted prevalence in adults aged 20-79 years of the European Union; its crude prevalence was estimated at 13.6% [155] – the prevalence of which is predicted to increase considerably in the next few decades [153]. Albeit new medical treatments and therapeutic possibilities, most people with type 2 diabetes still do not succeed optimal blood glucose levels [156,157]. This may mirror a poor organization of chronic illness care and a shortage of psychosocial support and self-management [157] . In 2001, the global Diabetes, Attitudes, Wishes and Needs (DAWN) survey delivered insights into the psychosocial demands facing people with diabetes and motivated stakeholders to implement person-centred diabetes care and actively include the person with diabetes in self-management with help from an interdisciplinary team of healthcare professionals. Later, the DAWN2 study [158] - a worldwide initiative between some international organizations – the International Diabetes Federation, the International Alliance of Patients' Organizations (IAPO) [159] and the Steno Diabetes Center, and Novo Nordisk for advancement of person-centred diabetes care – focused on how people with diabetes, family members and healthcare professionals understand diabetes care, pursuing a person-centred model that highlights the needs of the individual in the context of current chronic care, self-management and psychosocial support. Despite these efforts, healthcare systems are still struggling to adjust person-centred models of care and to motivate people with diabetes to self-manage their condition.

In Europe, almost 10 million people under 45 years of age have asthma [160]. The prevalence of asthma in the European Union (EU) is 8.2% in adults and 9.4% in children [160]. Asthma affects 6.8% of the Portuguese population [161]. Asthma is the fourth leading cause of death world yet still underrecognized and constitutes the most common chronic condition in children [162]. Although therapeutic and asthma patient-centred care have advanced over the last two decades [163-166], asthma is still often poorly managed [167,168]. Lack of self-management skills, especially failure to adhere to treatment regimens, is still prevalent and translates some of the factors commonly drawn on to explain poor outcomes in asthma care [169]. Asthma is still an important reason for hospital admission worldwide [159,170] and causes considerable limitations on the lives of both patients and their families [171,172]. The importance of an asthma patient involvement in their treatment has become evident as strategies for guided self-management have been developed and gradually improved. In the mid-1990s, early randomized studies showed that guided self-management with patients' own adjustment of anti-inflammatory medication based on symptoms and home peak flow measurements reduced exacerbations and other asthma events compared with traditional therapy [173]. Although research confirms that adherence to guideline-based care can improve asthma symptoms and outcomes, its use is missing. Guideline-based care ease advances in processes and outcomes, but if not tailored to the needs of patients, it is often useless [166]. Adherence to guideline-based care is challenging for multiple reasons. On one hand, factors such as clinical inertia, general practice barriers and time constraints along with the fact that clinicians often are not aware of the guidelines and have lack of trust in the ability of the patients to implement their recommendations, make guidelines challenging [174-180]. On the other, factors playing a major role are linked to the patients whether community and individual dynamics, such as poverty, environmental stressors, socioeconomic circumstances, social support and health literacy [181]. Recently, interventions focused on system and clinical supports considered that clinician education was not sufficient to increase adherence to asthma guidelines, and there was a need for tools to support behavior change more crucial than knowledge on asthma assessments. In USA, the Patient-Centered Outcomes Research Institute (PCORI) is supporting 8 projects aiming to understand why disparities in asthma care and outcomes remain persistent [182]. These projects, still underway, test multicomponent interventions developed with the input of patients, clinicians, and other key stakeholders, and are being implemented at the community, home and in the health system [183]. For instance, one of the projects, the Imperial County Asthma Comparative Effectiveness Research Project, tested different levels of strategies to support clinicians. Beyond the inclusion of asthma educators, they concluded that a new system should also include asthma care templates tailored to the patients' needs, sharing educational messages, and behavioral recommendations for the family. The key to improve outcomes was involving patients to work in partnership with clinician. Additionally, along with patient education tailored to meet the needs of the person by respecting their cultural beliefs they also incorporated a focus on health literacy and asthma knowledge [166], adopting a patient-centred approach

2. Objectives

Health literacy is now a key consideration for health research and programs of health promotion worldwide [1,2,41]. Contributes from research are rapidly increasing understanding of the enormous potential that optimizing health literacy can have in improving health and well-being of the populations [8]. However, measures of health literacy have been predominantly focused on a limited range of health-related literacy and numeracy skills [40], neglecting a more extensive set of dimensions of health literacy, such as the contextual nature of reading and writing in health care settings, how patients make sense of their experience (particularly, in the management of chronic conditions), the resources draw on (types of support, social networks and the role of others) and how they communicate with health professionals (barriers and facilitators).

To address this gap, Edwards proposes the concept of distributed health literacy, which describes how individuals draw on the health literacy skills of others from their social network to seek, understand and use health information: "*Health literacy is distributed through family and social networks. It allows people living with a long-term condition to draw on their social network for support with health literacy-related tasks such as managing their condition, interacting with health professionals and making decisions about their life*"[49]. Literature show that accessing, understanding, evaluating and using health information is not often an individual task, supporting that individuals with health literacy low scores might still manage successfully complex health conditions such as type 2 diabetes [58,59]. They may able to manage their condition without fully understand it or rely on significant others – *health literacy mediators*, the individuals who share their health literacy skills with others. According to Wagner et al. [50] combining several aspects of literacy possessed by each individual, it may allow that they function as more fully literate persons [49]. Baynham [52] describes literacy mediators as *'a person who makes his or her literacy skills available to others, on a formal or informal basis, for them to accomplish literacy purposes*.' Notwithstanding, the role of the social networks in the management of chronic health conditions is still a grey zone of knowledge within a health literacy research context.

Thus, this thesis focus on a broader and deeper understanding of health literacy for guiding the health system of public health practitioners, health professionals, and community agencies towards embracing definitions and policies to resolve mismatches between the needs of individuals and the demands of health systems [33]. The conception that health literacy is collectively achieved defies individualised notions of responsibility and risk, which tends to underline current public health policies [184]. This brings additional challenges both for the public health policies and the research field, and make these arenas of expertise rethink the way health literacy is understood and studied. Consequently, this calls the need for the creation of more comprehensive interventions and public health infrastructures, professionals and services that both foster and support the 'distributed' health literacy [93]. In the research field, this implies the use of a narrative-oriented approach to accurately capture the broader dimensions of the DHL. Narratives may expand and enrich the research agenda, by providing meaning, context, and perspective for the patient's difficulties in self-management and defining "how, why, and in what way he or she is ill" [97]. This is critical in the management of chronic conditions. People suffering from chronic conditions, such

as asthma and type 2 diabetes, have complex and continued needs (medical, physical, psychological and social), and narratives are fundamental to approach the experienced difficulties in everyday living, providing insight into the respective experience, enabling access to knowledge, self-management skills and health networks [107].

To understand the processes of the DHL in chronic conditions, two priority cases set by the Portuguese National Health Plan (2012-2016) were purposively selected for analysis - asthma and type 2 diabetes. Although both conditions have different medical regimens recommendations, which asks for different knowledge and skills from patients, the link can be established through the analysis of common types and settings of support. In addition, these two conditions have the most robust evidence base for the effectiveness of implementing supported self-management, as for example, patients and peer support groups [151], and they both are considered a 'family issue' condition, where management occurs very typically in the context of routine family activities.

This thesis aims to explore the interactions between the demands of health systems and the skills of individuals, as well as the context and complexity of skills and support identified as necessary for patients with chronic conditions to be considered 'literate' in relation to their health.

To accomplish this general aim, three studies were performed, with the following specific objectives:

1) To explore how social networks and personal experiences are a portrait of the DHL, mapping out health literacy mediators (those who *makes his/her literacy skills available to* others *for them to accomplish specific literacy purposes)*, and how they enable self-management skills in patients with i) type 2 diabetes (**Paper I**) and ii) asthma (**Paper II**).

2) To analyze the perceptions of patients with moderate to severe persistent asthma about family influence in daily management of disease, taking into account the levels of literacy skills and the health information seeking behavior (**Paper III**).

3) To explore the perceptions on the constraining and facilitating factors to patient-centered communication in clinical encounters of patients with type 2 diabetes and the providers involved in their care (**Paper IV**).

3. Methods

This work is based on three qualitative and cross-sectional studies: Study 1. Individual interviews with people with type 2 diabetes and asthma; Study 2. Individual interviews with people with moderate to severe asthma and; Study 3. Focus group with people living with type 2 diabetes and healthcare professionals (Table 1).

In data collection, storage, analysis and dissemination, procedures were developed to guarantee data confidentiality and protection. All participants formalized their collaboration through a written informed consent according the World Medical Association's Declaration of Helsinki. Ethical approval was granted by the Research Ethics Committee of the Institute of Public Health of the University of Porto, by Research Ethics Committee of Hospital de Santo António and by Research Ethics Committee of Hospital de São João.

Table 1. Study design

	Study 1		Study 2	Study 3	
	People with type 2 diabetes	**People with asthma**	**People with severe asthma**	**People with typical range of diabetes micro and macrovascular complications**	**Health professionals**
Setting	Primary Care Center of Porto District	Primary Care Center of Porto District	One public Hospital and a private Hospital in Porto	Health Center	Research Institute
Sampling	26 interviews	20 interviews	35 interviews	**Focus group 1** (n=7): without diabetes complications **Focus group 2** (n=7): diabetic retinopathy **Focus group 3** (n=5): diabetic nephropathy **Focus group 4** (n=7): diabetic foot **Focus group 5** (n=7): ischemic heart disease or cerebrovascular disease	**Focus group 6** (n=6): primary care physician; nurse; nutritionist; pharmacist; ophthalmologist; vascular surgeon; **Focus group 7** (n=6): endocrinologist; nurse; nutritionist; pharmacist; psychologist, nephrologist
Period of data collection	2014 to 2015	2014 to 2015	2012 to 2013	2015 to 2016	2012
Interview Guide	MINI – McGill Illness Narrative Interview	MINI – McGill Illness Narrative Interview	MINI – McGill Illness Narrative Interview	Semi-structured interview guide	Semi-structured interview guide
Content analysis	Grounded Theory	Theoretical Thematic Analysis	Grounded Theory	Grounded Theory	Grounded Theory

3.1 Study 1 – People with asthma and type 2 diabetes

This study aimed to explore how patients (people with asthma or people with type 2 diabetes) draw on their social network for support with health literacy-related tasks, mapping out health-literacy mediators for each individual, and how they enable self-management skills and knowledge about their health condition (asthma or type 2 diabetes).

Between October 2014 to December 2015, 51 patients with asthma or type 2 diabetes were invited by doctors and nurses of the primary care center to participate in our study, 46 accepted. Qualitative interviews were conducted to patients with asthma (n=20) or type 2 diabetes (n=26) in a primary care facility in the district of Porto. The setting of a primary care center was chosen in order to maximize our probability of finding patients without major complications of asthma and type 2 diabetes.

Participants were purposively sampled to include both men and women with different times of diagnosis (patients living with the condition for long time versus patients recently diagnosed). In addition, a heterogeneity sampling was used for maximum variation of views and experiences. The criteria for closure of analysis were theoretical saturation [183,184] - recruitment continued until no new theme emerged from the interview data. Interviews were conducted in a private room, ranging from 29 to 90 minutes, with an average of 55 minutes. All interviews were digitally audiotaped and then transcribed verbatim.

Semi-structured interviews were conducted by the PhD candidate. An adapted version of the McGill Illness Narrative Interview (MINI) [185] was used. MINI is a flexible tool which is widely used on health research in a range of settings and conditions [186,187], bringing up the experience of respondents and embedding it within stories that uncovered sociocultural patterns and experiences within their unique context[185]. It comprises a common core of modules aimed at eliciting narratives of the experience of the interviewee in relation to a specific condition or set of conditions and at inquiring the way he/she constructs knowledge of the condition. It also allows the exploration of the participants' representation models, meanings, experience and its relation to behaviour, along with their health- and treatment- seeking. MINI is divided into five sections: 1) *Initial Narrative* – intentionally unstructured, allowing interviewees to tell their story in their own way and on their own terms; 2) *Prototypes* – more structured, aiming to elicit narratives on prototypical experience of self and others; 3) *Explanatory models* – causal type of reasoning and knowledge about the condition; 4) *Help seeking and service utilization* – optional, inviting the interviewee to a narrative of their experience with health services, treatment and hospitalization; 5) *Impact of illness* – aiming to explore if and how patients believe the illness has led to changes in their identity and way of life since its onset. A sixth module was added to the original version of MINI, focusing on questions about sources of health information and social support ("If you had to name someone you know to help you with a health-related decision, who would you name?"; "Do you usually go accompanied to medical consultations? If yes, by whom?").

Based on grounded theory [188] interviews of patients with type 2 diabetes were analyzed as case-based and process-tracing-oriented, using NVivo 10 (QSR International, USA, 2013). The set of procedures was to constantly compare, contrast and synthesize and code data by theme and subsequently by thematic category [189]. Thus, interview transcripts were reviewed and read several times for interpretation, and then submitted to content analysis using systematic coding procedures and constant comparison methods.

Theoretical thematic analysis [190] was employed to interviews of patients with asthma, also with the assistance of NVivo 10 (QSR International, USA, 2013). Themes were previously coded based on the previous interviews. Open coding was used to illustrate the specific features of the data deriving from similar and recurring ideas and phenomena; coded data were then constantly compared within and between the transcripts to consistently identify linkages and patterns throughout the data. A process of continuous refinement was thus undertaken by repeatedly reading the transcripts and grouping similar ideas into themes, aiming to develop inductive content categories that allows the theory to emerge from the data. Themes were not mutually exclusive and represented fluid rather than discrete and sequential categories.

The bulk of the analysis was handled by the PhD candidate. Coding was then discussed with supervisors to explore additional perspectives and patterns of the data until consensus was reached, aiming to prevent untimely ceasing of the analysis and therefore enhancing reliability and rigor [189,191].
Quotes from participants are presented to illustrate related key points. Pseudonyms are used in the quotes extracted from participants' discourse for anonymity.

3.2. Study 2 - Patients with moderate to severe asthma

This study aimed to analyze the perceptions of patients with moderate to severe persistent asthma about family influence in daily management of disease, taking into account the levels of literacy skills and the health information seeking behavior.

Between January 2012 to January 2013, 35 patients with moderate to severe persistent asthma agreed to participate in this study. Inclusion criteria comprised adults, who had been diagnosed with moderate to severe asthma, at least 12 months before the interview.

Patients were randomly selected by doctors, only purposively sampled to include both men and women. Interviews were conducted in a private room in the hospital, where participants read and signed the informed consent. Interviews took place before or after their medical consultation, according to participant preference and availability. The aim was to treat each subject as a *case*, associated with a specific illness trajectory and experience and selected through *sampling for range* [184]: rather than looking for "average" patients, researchers were interested in the range of experiences which allowed an understanding of illness as part of the lived experience of patients.

Semi-structured interviews were conducted by the PhD candidate. An adapted version of the McGill Illness Narrative Interview (MINI) was used, as described in the previous section.

Based on grounded theory [188], interviews of patients with asthma were analyzed as case-based and process-tracing-oriented, using NVivo 10 (QSR International, USA, 2013). Process-tracing was achieved through coding each interview to identify categories associated with the processes of interest, incorporating constant comparison of the coded interviews, and exploration of deviant cases.

The criteria for closure of analysis were theoretical saturation [183]. Open coding was used to illustrate the specific features of the data deriving from similar and recurring ideas and phenomena; coded data were then constantly compared within and between the transcripts to consistently identify linkages and patterns throughout the data. A process of continuous refinement was thus undertaken by repeatedly reading the transcripts and grouping similar ideas into themes, aiming to develop inductive content categories that allows the theory to emerge from the data. Themes were not mutually exclusive and represented fluid rather than discrete and sequential categories.

The bulk of the analysis was handled by the PhD candidate. Coding was then discussed with authors to explore additional perspectives and patterns of the data until consensus was reached, aiming to prevent untimely ceasing of the analysis and therefore enhancing reliability and rigor[189,191].

Quotes from participants are presented to illustrate related key points. Pseudonyms are used in the quotes extracted from participants' discourse for anonymity.

3.3. Study 3 – Patients with type 2 diabetes and their health professionals

This study aimed to explore the perceptions on the constraining and facilitating factors to patient-centered communication in clinical encounters of patients with type 2 diabetes and the providers involved in their care.

Participants were purposively sampled to include the standard range of areas of expertise involved in the care of type 2 diabetes patients in Portugal, and the typical range of diabetes micro and macrovascular complications. Within groups heterogeneity was pursue regarding age and professional experience/disease duration. We conducted two focus group of health professionals in 2012, in a research institute and five focus groups of patients between 2015 and 2016 in a health care center for the group without complications or hospital for the remaining groups.

Focus group followed a semi-structured set of questions aimed at understanding the experiences in communication between people living type 2 diabetes and their healthcare professionals. Questions covered factors that constrain and facilitate communication, patients' information needs, and methods used for gathering and providing information. All the focus group included a trained moderator and a co-moderator. Focus group discussions lasted from 56 to 93 minutes, with a median duration of 90 minutes. The audio of the focus group was recorded, professionally transcribed verbatim and checked for accuracy.

Data were analysed independently by two researchers, including the PhD candidate, using grounded theory, with NVivo 10 (QSR International, USA, 2013), and merged by consensus following continuous and iterative discussions, to strengthen coding consistency. This triangulation was further supported by researchers' different backgrounds (medicine and sociology). In addition, classifications were always discussed and validated by one of the supervisors. Open coding, axial coding and selective coding were used. Quotations with similar meanings were synthesized into categories (open coding), which were then put together into themes (axial coding), and then into core themes (selective coding). During selective coding, inductive themes were loaded with interpersonal patient-centred communication theory in consultation with existing literature.

4. Results

4.1 Paper I. Distributed health literacy among people living with type 2 diabetes in Portugal: Defining levels of awareness and support

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ORIGINAL ARTICLE

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Distributed health literacy among people living with type 2 diabetes in Portugal: Defining levels of awareness and support

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Abstract

This study embraces a patient-centred and narrative-oriented notion of health literacy, exploring how social networks and personal experiences constitute distributed health literacy (DHL) by mapping out health literacy mediators of each individual and how they enable self-management skills and knowledge of health conditions. Semi-structured interviews with 26 patients with type 2 diabetes were conducted in a Primary Care Center of Porto (Portugal) from October 2014 to December 2015. Data were collected based on McGill Illness Narrative Interview (MINI). Following the grounded theory, interviews were analysed as case-based and process-tracing-oriented. Three awareness narratives emerged: (i) a narrative of minimisation revealing minimal impact of diabetes in patients' lives and daily routines, resignation towards "inevitable" consequences of the diagnosis and dependence of a large network of health literacy mediators; (ii) a narrative of empathy, where patients tended to mention readjustments in their lives by following medical recommendations regarding medication without criticism and with few health literacy mediators; (iii) a narrative of disruption, with patients highlighting the huge impact of diabetes on their lives and their individual responsibility and autonomy with respect to the management of diabetes and the search for alternatives to medication, relying on a very restrictive network of mediators. Exploring meanings given to diagnosis, identifying health mediators and analysing the structure of social networks can contribute to understand the distributed nature of health literacy. Assessing DHL can assist health professionals and those providing care in the community in promoting health literacy and providing models for a more patient-centred health system.

KEYWORDS
distributed health literacy, health mediators, illness narratives, patient-centredness, social networks, type 2 diabetes

1 | INTRODUCTION

In recent years, practices of health education and communication have been challenged by findings connecting literacy to health. Addressing health literacy is a daunting task as it involves social and individual factors, mediated by education, culture and language, as well as individuals' social networks (Lee, Arozullah, & Cho, 2004; Nielsen-Bohlman, 2004).

The published literature has been increasingly focused on how limited individual health literacy negatively affects patients' ability to understand health information, the communication with physicians, and compliance with recommendations and treatments (Clement, Ibrahim,

Crichton, Wolf, & Rowlands, 2009; Coulter, Parsons, & Askham, 2008; Mantwill & Schulz, 2015; Miller, 2016). If patients have difficulties in obtaining, processing and understanding basic health information, their capacity for self-care will be limited—a particularly critical aspect in chronic conditions such as type 2 diabetes (Williams et al., 1998), where 95% of illness management depends on the patient (Anderson, 1985; Russo & Walker, 2001). Previous studies, however, have shown that some patients with lower scores on individual health literacy still keep diabetes under control (Osborn, Bains, & Egede, 2010; Powell, Hill, & Clancy, 2007). They may be able to manage their condition without fully understanding it, or rely on significant others—health "literacy mediators" e.g. caregivers, family, friends (Edwards, Wood, Davies, & Edwards, 2013; Pooley, Gerrard, Morton, & Astbury, 2001) or health professionals involved in routine clinical care (Baynham, 1995)—for managing the condition.

This paper examines the entanglement of individual skills and social support through the lenses of the concept of distributed health literacy (DHL)—defined as literacy dispersed throughout a group, including resources provided by a personal network of individuals and social media (Edwards, Wood, Davies, & Edwards, 2012; Lepore, 1991). The paper focuses on how patients with type 2 diabetes draw on their social network for support with identified health literacy-related tasks. Our proposal goes beyond the focus on quantitative measurement of health literacy or on assessment of individual capacities of reading and comprehension and numeracy skills (Andrus & Roth, 2002; Nutbeam, 2000; Williams et al., 1995). Instead, we explore the interactions between the demands of health systems and the skills of individuals, as well as the context and complexity of skills and support identified as necessary for patients to be considerate "literate" in relation to their health (Berkman, Davis, & McCormack, 2010; Sørensen et al., 2012) .

The development of broader measures of health literacy, with deeper understanding of DHL, may benefit from the analysis of illness narratives of patients with type 2 diabetes (Greenhalgh, 2009), in the sense that the point of view of lay experiences and "patienthood" may help unpack chronic illness self-management behaviour since diagnosis (Bury, 2001; Flyvbjerg, 2006), and self-management support (which has been identified as relatively underdeveloped in Europe; Elissen, Nolte, & Knai, 2013; Kousoulis et al., 2014; Foss et al., 2015). Analysing illness narratives that stem from diagnosis contributes to the theoretical approach of social construction of illness (Sontag, 1978), which has particular relevance for understanding DHL. This study embraces a patient-centred and narrative-oriented notion of health literacy, exploring how social networks and personal experiences are a portrait of the DHL, mapping out health literacy mediators for each individual, and how they enable self-management skills and knowledge of health conditions.

What is known about this topic

- Current definitions of health literacy (HL) with its quantitative measurement instruments leave a gap in understanding.
- Some patients with lower scores on individual HL still successfully keep conditions, such as diabetes, under control.
- Involvement of family and friends is advocated as one of the core dimensions of patient-centred care.

What this paper adds

- Social networks with high-density provides more emotional and instrumental support than do less dense networks.
- People-centred health systems need to focus on DHL rather than just emphasising individual health literacy.
- It is important to create hybrid spaces for dialogue between multiple mediators in each individual networks.

2 | METHODS

This is a qualitative and observational study. From October 2014 to December 2015, 31 people diagnosed with type 2 diabetes, attending a Primary Care Center in Porto District (Northern Portugal), were invited by doctors or nurses to participate in the study—26 accepted. Participants were purposively sampled to include people with a diagnosis for more and less than 10 years, men and women aged around or over 50 years. Heterogeneity sampling was used for maximum variation of views and experiences, until theoretical saturation was reached—the point when no new, significant data emerge from data analysis (Strauss & Corbin, 1998).

Data were collected based on the McGill Illness Narrative Interview (MINI), previously applied in another Portuguese study about health knowledge of people with asthma and breast cancer (Abreu, Borlido-Santos, Vilar-Correia, & Arriscado-Nunes, 2012). MINI is a semi-structured ethnographic and theoretically driven interview schedule, designed to elicit narratives and status of health knowledge (Groleau, Young, & Kirmayer, 2006), covering the following sections: (i) *Initial Narrative*—intentionally unstructured, allowing interviewees to tell their story in their own way and on their own terms; (ii) *Prototypes*—more structured, aiming to elicit narratives on prototypical experience of self and others; (iii) *Explanatory models*—causal type of reasoning; (iv) *Help seeking and service utilisation*—inviting the interviewee to a narrative of their experience with health services, treatment and hospitalisation; (v) *Impact of illness*—aiming to explore if and how patients believe the illness has led to changes in their identity and way of life since its onset. Data were analysed to enable the identification of distinct groups of narratives about the experience of illness in relation to diabetes. For the purposes of this paper, two additional topic questions were addressed to explore the role of health mediators: "Do you usually go accompanied to the medical visits (if yes, by whom)? If we ask you to choose someone to help you in a health-related issue, who would you choose and why?" (it was stated to the patients they could mention more than one person).

Interviews were conducted by the first author in a private room, ranging from 29 to 90 min (average 55 min). All were taped, professionally transcribed verbatim and checked for accuracy.

Based on grounded theory (Charmaz, 1983; Bryant & Charmaz, 2010), interviews were analysed as case-based and process-tracing-oriented, by the first author, using NVivo 10 (QSR International, USA, 2013). Coding of participants' responses was discussed by three of the authors. Process-tracing was achieved through coding each interview to identify categories associated with the processes of interest, incorporating constant comparison of the coded interviews, and exploration of deviant cases.

The findings are reported below with verbatim anonymised quotes from interview transcripts translated by the authors.

All participants formalised their collaboration through a written informed consent. Ethics approval was granted by the Research Ethics Committee of the Institute of Public Health of the University of Porto.

3 | RESULTS

Three themes emerged from data analysis (Table 1): (i) *dealing with the diagnosis*; (ii) *self-management skills*; and (iii) *health literacy mediators*. After the classification of each interviewee's positioning in relation to these themes, participants were grouped according to the following narratives, determined by the response to diagnosis: (i) narrative of minimisation—patients claiming minimal impact of diabetes on their lives and daily routines; (ii) narrative of empathy—patients tending to follow medical recommendations without criticism; (iii) narrative of disruption—patients highlighting a huge impact of diabetes on their lives and their individual responsibility on illness self-management. Participants' characteristics are described in Table 2.

3.1 | Group 1. Narrative of minimisation

3.1.1 | Dealing with the diagnosis

Interviewees enacting a narrative of minimisation reveal a low impact of diabetes in their lives and daily routines, which remained "normal" after diagnosis, and minimise or disguise symptoms when telling their stories as a way to dismiss the seriousness of their condition. They appear to discount feelings of being different after diagnosis, in order to maintain pre-illness identity intact by means of two repertoires: (i) deletion, a narrative mechanism that suppresses the gravity of diabetes when resetting it as a condition equivalent to other "non-serious" conditions, such as high cholesterol or hypertension; and (ii) purification, reasserting the continuity of minimisation by dismissing the diagnosis of diabetes as a disruptive moment or by constructing diabetes as a family condition or as a result of stressful situations that could not be prevented:

TABLE 1 Themes and narratives

	Dealing with the diagnosis (explores attitudes, trajectories and levels of awareness and knowledge)	**Self-management skills** (explores the access to health services and how they manage diet, physical exercise and medication)	**Health literacy mediators** (explores sources of support—formal, informal or other; to types of support—pragmatic, informational and emotional. The actors, networks and processes)
Narrative of minimisation	Acceptance of diagnosis as inevitable. Do not know the causes of diabetes. Diagnosis sometimes does not lead to medical intervention.	Use of non-technical language, little or no understanding of the health condition and no interest in further information details. Information provided by the doctor or other health professional, they usually interact, is enough to manage the condition. The idea of searching more about diabetes outside the medical consultation is often regarded as mistrusting the doctor.	*Largest network of "literacy mediators"*: facilitators from formal (health professionals) and informal (relatives) settings, the type of support is mostly informational.
Narrative of empathy	Making sense of symptoms, point causes for diabetes; give advice to others.	Display some understanding of health information, use of a mix of technical and non-technical language, know the name of medications, although with some difficulties of pronunciation and the purpose of each. Maintain that they received enough information about diabetes for their needs; have a more active participation in treatment, good relationship with doctors.	*Intermediate network of "literacy mediators"*: mostly from formal settings; type of support is informational and emotional.
Narrative of disruption	Diagnosis is biographical disruptive, leading to an active attitude to deal with diabetes	Good to excellent understanding of health information, use of appropriate technical language, often more information about condition and treatments available, searching treatments outside the standard public health system.	Smallest network of "literacy mediators": Tendency to be very independent in the management of diabetes, sources of support are mainly the doctor and Internet.

TABLE 2 Participants' characteristics

Name (alias)	Age	Educational level	Household composition	Years since diagnosis	Diabetes in the family
Minimisation					
Alice	49	Elementary	Husband	5	Yes
Beatriz	70	Elementary	Alone	31	Yes
Diana	74	Elementary	Husband	31	Yes
Raquel	54	Elementary	Husband and daughter	3	Yes
César	67	Elementary	Wife	16	Yes
Gabriela	75	None	Husband	21	Yes
Júlio	57	Secondary	Alone	8	Yes
Irene	48	Elementary	Parents	4	Yes
Hugo	56	Elementary	Wife	9	Yes
Isabel	71	Elementary	Alone	Do not know	Yes
Laura	84	None	Alone	15	No
Lourenço	54	Elementary	Wife and daughter	Do not know	Yes
Empathy					
Carla	75	Elementary	Son	>20	No
Henrique	78	None	Wife	21	Yes
José	71	Elementary	Alone	11	Yes
Isaac	77	None	Alone	21	Yes
Helena	70	Elementary	Husband	31	Yes
Ana	65	Elementary	Husband and daughter	17	Yes
Luís	72	Elementary	Wife	Do not know	Yes
Madalena	63	Elementary	Husband	11	Yes
Rafael	67	Elementary	Alone	Do not know	Yes
Miguel	69	Elementary	Wife and daughter	16	Yes
Disruption					
António	41	High	Wife and son	5	Yes
João	64	High	Wife	10	Yes
Nuno	71	High	Alone	2	Yes
Margarida	37	High	Husband and son	5	Yes

For me diabetes was like some other disease, just like the flu.

[Laura]

I was already expecting this [diabetes], because when you have your both parents as diabetics, someone (one of the siblings) will inherit it. My mother was always telling me: "you have to do blood tests. I inherited this from your grandfather!" And one of the times I did a blood test, turns out, it was positive. We just have to accept (…) For me it is a condition like any other disease. Some people have high cholesterol, others have hypertension. (…) So far, I have nothing that convinces me that it's that serious.

[Alice]

I am from a diabetic family. One of my brothers (diabetic) amputated half of his leg. He is 2 years younger than me, but I had another one [brother] that also amputated his leg, he was older than me but already passed away. And my other sister (also diabetic) amputated her foot. We

inherited this from our parents. There's nothing we can do (…) But my diabetes is minimal, I don't even need to take insulin.

[Isabel]

This minimisation of diagnosis contributes, in some cases, to the non-adherence to, or even absence of, medical treatment for a certain period, in particular when there are issues considered more important than diabetes, such as comorbidities or even financial commitments:

I'm very attached to my older son (…) and one Saturday (…) he didn't come home to sleep. I cried all night (with worry)! (…) He was all right, but that night I started to feel ill. I was so tired, my body hurt and then it (diabetes) began. (…) I didn't follow any treatment for many years, [because] I had other concerns, I had to work to pay my house.

[Beatriz]

3.1.2 | Self-management skills

The difficulties in adherence to changes of lifestyle are justified by three main arguments: absence of pain; the belief that "diabetes will never heal"; and lack of awareness about prognosis. Poor adherence is slightly improved when interviewees become aware of the chronicity of diabetes or of its worst consequences and complications. Afterwards, interviewees focus on prioritising adherence to medication, while showing difficulties in knowing how to properly follow the diabetic diet, and without referring to exercise as part of treatment. Participants attributed symbolic connotations to diabetes, as a way of reflecting their own understanding that it would not heal exclusively through medical intervention, such as, the idea of diabetes being a plague:

My sister usually tells me that bad things can happen [as consequences of diabetes]. But I am very confident (…) and I think I have everything controlled. At least, I feel no pain!

[Lourenço]

I did the medication that my doctor prescribed me and I was ok. I could eat all I wanted, medication was enough. But now, I don't know why, I can't! It was never this bad. I can't eat anything, because it is always high (glycemic level). I lost 18 kgs in the last months. For me diabetes is a plague, a plague! I have doubts about everything. (…) There are bad diseases, but if we treat ourselves we get better, (…) but not in diabetes. (…) When I was diagnosed I didn't think it was bad, I thought there was a cure. (…) But [now I know that] my diabetes will never heal.

[Laura]

Although these patients usually do not remember the names of the drugs and their specific purposes, they can describe the colours of the pills or boxes:

I take one pill in the morning and another in the evening. (…) I don't remember [the name]. It's a box, pink and white. It's a generic. She (the doctor) says it's for diabetes.

[Alice]

I can't tell you the name of the medication [doesn't know]. I take insulin now, and I take 13 pills a day [not only for diabetes but for other chronic conditions]. But I didn't start being medicated right away. I was diagnosed in France [31 years ago], and the doctor prescribed medication, but I didn't felt any pain, I was only tired… Life was hard back then. So, I didn't do anything.

[Beatriz]

3.1.3 | Health literacy mediators

Interviewees enacting a narrative of minimisation report the largest number of literacy mediators (Figure 1—Group 1), mainly health professionals they usually interact with (doctor, nurses and chemist) and also family members with type 2 diabetes or living in the same household.

They search information about diabetes mainly inside their formal one-way doctor/patient relationship, revealing high levels of trust on their own doctors—responsible for prescribing medication or treatments. They also state that the nurses working at the health centre where they usually are treated as important for managing the condition, controlling blood sugar or feet care:

I pay high, high attention to what the doctor says. I try to follow his advices, to walk a little, but I don't do it that often, once in a while I walk with my dog. Usually it is the nurse that tests my glucose, when I came to the medical visit. And that's it. I have the machine and everything, but I don't do it [control blood sugar] … well, maybe I don't want to get used to it. (…) I understand nothing of that [glucose levels]! I ask the doctor if it's good or bad, that's all I need to know.

[Júlio]

Informal support is provided by family and friends, usually those sharing from the same condition, and relies on sharing experiences, as well as help in decision-making about treatments and changes in daily routines. Besides this, the responsibilities of the significant other (caregiver) include management of medication (e.g. organising the pill boxes) or controlling diet:

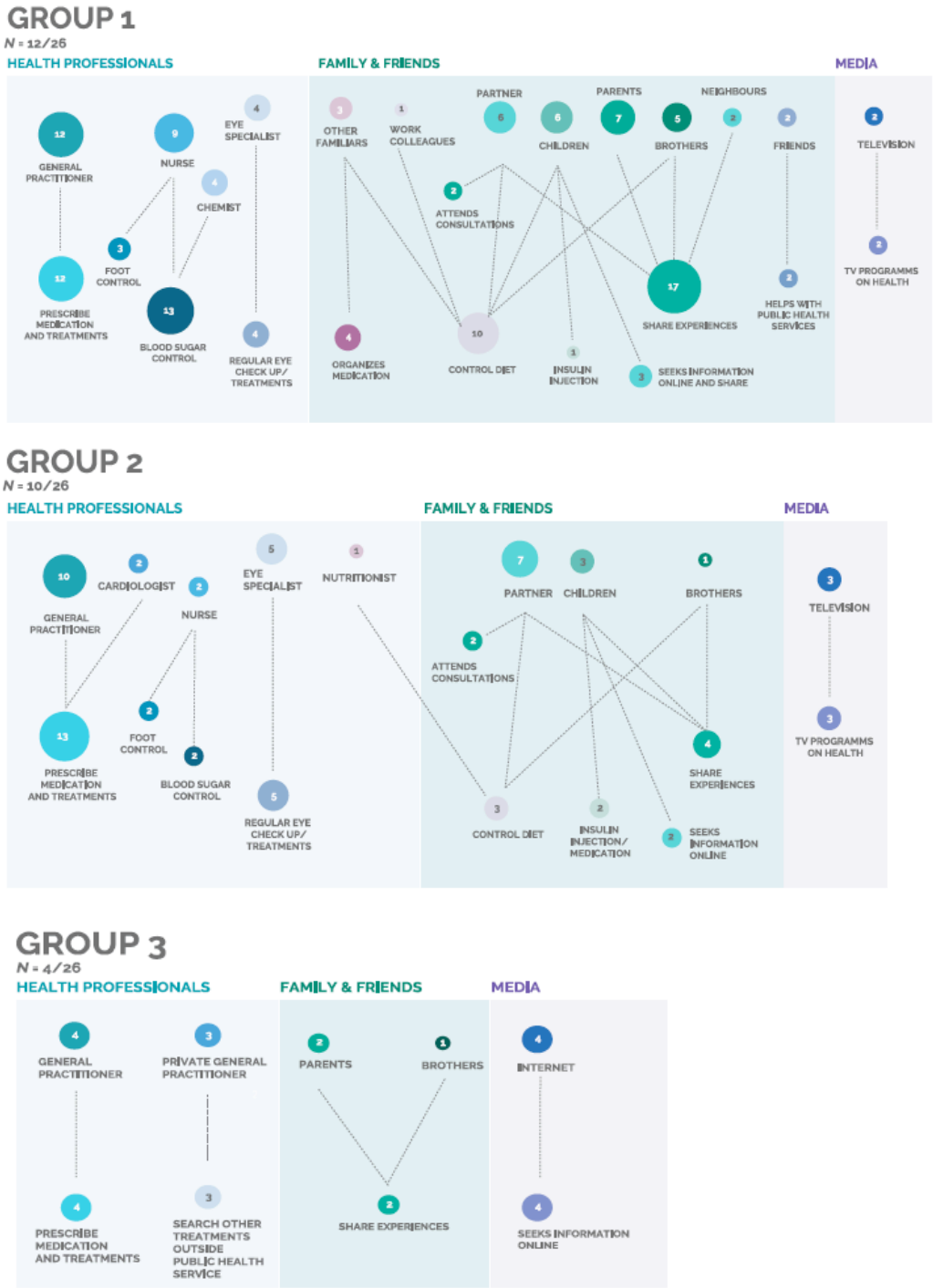

FIGURE 1 Map of health literacy mediators and practices divided into three groups. *Note*. Circles are the frequency that each mediator was mentioned and lines are the association with different health literacy practices. [Colour figure can be viewed at wileyonlinelibrary.com]

My granddaughter puts all my pills in a small box (with divisions) like that: in the morning; after breakfast; lunch; and in the evening. I just go there and pick them. (…) When I need something, I just tell her: "I need this, that and that, please come here that I need you to see something for me." I just call for my granddaughter (…) and she comes.

[Beatriz]

I cannot say that I control myself 100% (in terms of diet), but my wife pays more attention to that and often she boils something for me, like potatoes, fish, or something healthier. And she cooks something else for her. (…) Also, when my sister comes to visit me, she usually gives me advices (she has been diabetic for a longer period of time) and I learned from her.

[Lourenço]

When I speak with other diabetics, like my father, and they tell me their glycemic levels and I tell them mine, those who usually have high glycemic levels frequently say to me: "Oh, that's not diabetes!" My diabetes are not the bad ones.

[César]

I don't have the freedom I used to have. Two weeks ago, my glycemic levels were permanently above 300, I couldn't control it. I was desperate because I didn't know what I was doing wrong. My daughter tried to help. She came to change my sticks from the machine. She wanted to know if with new ones things would get better. And they did.

[Hugo]

3.2 | Group 2. Narrative of empathy

3.2.1 | Dealing with the diagnosis

Interviewees enacting a narrative of empathy mention readjustments in their lives after the diagnosis of diabetes, including the strict following of medical treatments and recommendations, and how they empathically self-identify as a person with the condition of diabetic.

In this group, diagnosis is a starting point for the process of sense-making of previous symptoms. These patients embed the diagnosis of diabetes in an interpretative approach, providing satisfactory explanatory models that span lay and professional knowledge. They try to search for causes, through explanatory models about individual lifestyles trajectories, as a pathway to understanding and empathically deal with the diagnosis:

At the moment of diagnosis, the doctor explained to me what diabetes was, and told me to control it every day. We talked about all the recommendations I had to follow. And 3 months after this appointment, I had my second visit and I told the doctor:" It's done. That's it, my diabetes is where I want it to be. I'm adjusted to it".

[Rafael]

For more than 30 years I worked in a construction company, we worked in many different places in the world, and all our meals were made at the company canteens (…) And you know how canteens food is, rice or pasta every single day. I think that diabetes was being created all those years of bad diets. That's how diabetes appeared in my life.

[Miguel]

I had no idea what diabtes was No idea! I only used to feel very thirsty, my mouth was always very dry. I wondered what that could be? Then I told the doctor about the symptoms and he (…) asked me to have a blood test. (…) I thought I also had bronchitis: "Could it be from bronchitis? Could it be from sleeping with my mouth open?"

[Luís]

3.2.2 | Self-management skills

The interviewees enacting a narrative of empathy are aware of the main components of self-managing diabetes—medication, diet and exercise—but attribute more importance to adherence to medication. They identify the names and purposes of drugs, despite difficulties in pronouncing their names, and have sufficient knowledge of what is proper diabetic diet, although they reveal difficulties in complying with it. Following a "diabetic diet" is a biggest difficulty they have, even being aware of the harm of not complying with it. Miguel, for example, feels pressure to get to like what he can eat while being unable to eat what he would like:

Now I take Brizidon, I take Vizicor for cholesterol; I take Tramolit for the thromboses; I take Atacan for blood pressure, and nothing else. For pressure, I take Atacan in the morning with the Brizidon for the "devils" (in Portuguese "diabretes"≈diabetes) (…) I eat fish, lots of fish, but it is not "that" diabetic diet [recommended by the doctor]. (…) If I am eating my diet and next to me there's a colleague eating (some other food), I start looking at him, and not at my food, my eyes don't stop viewing his food! Because mine doesn't have any taste, nothing.

[Miguel]

While medication and diet are directly connected to the control of glucose levels, exercise combined with diet is described as a way of feeling healthier. In addition, exercise is described as a "tool" to lower glycemic levels and to eat beyond the strict diabetic diet:

> *At the end of the month I will have an appointment with a nutritionist. She usually tells me I can't eat this or that, but I am aware of those things. If I want to eat more, I know that if, before the meal, I go to my backyard to dig a little or make some physical exercise, I can eat more things that I like.*
>
> *[Henrique]*

> *The doctor told me to walk every day, and I walk every single day, 6–7 kms. When I feel a little dizzy I know if it is because I walked too much and did too much effort or the opposite. I know right away what it is. I view my glycemic levels (just to confirm), and there it is. So, I immediately do something to stabilised glucose, usually with hiking. I walk a lot, I just need to do some physical exercise and things get better.*
>
> *[Luís]*

3.2.3 | Health literacy mediators

This group has an intermediate number of health literacy mediators (Figure 1—Group 2), and relationships with health professionals are described as two-way communication. Most of the information, doubts and concerns patients have are shared in consultations with doctors, and treatments are "negotiated." These interviewees are aware of when medication does not "work" properly and are sensitive to symptoms caused by it.

> *I know very well the medication and the effects. For example, one medication, Lasix, I used to take it in the morning but I stayed so bloated with that. I could not go anywhere, because I have to go to the bathroom every hour. So, I decided only take it in the afternoon, so like that I can do things during the day. But those are my conclusions! The doctor once tried to change to a generic, but it was such a mess, I felt very badly, I didn't adapt to it. (…) We discussed the situation and stopped all generic medication.*
>
> *[Helena]*

Media may function as a source of empowerment for some participants, specifically those with accessible language and images, easy to understand:

> *I've watched so many things (on TV) and people speaking about diabetes also! But usually they mention diabetes at an advanced stage. (…) I see every day the programme from TV Globo about health, and I have learned so many things not only about diabetes. The eyes, the nose, the throat, they explain everything so well. I understand everything, I see my symptoms.*
>
> *[Carla]*

Although individual use of the Internet is rare, participants frequently comment that someone close to them (e.g. son or daughter) search information about diabetes on the Internet. Diabetes tends to be managed by all household members, who provide information about diet, interpretation of symptoms or help with medication:

> *My wife was diabetic (she past away), and so is my son. Once my doctor prescribed one medication and I didn't feel good after taking it, it had no effect. My son told me to stop taking it and I told that to my doctor: "Doctor what if I would change medication? You are the expert but this medication does not let me feel well". And he did change my medication.*
>
> *[Isaac]*

> *My son goes to the internet (to search for health information), and I don't like him always telling me the same. He is always saying: "This is bad for you, don't eat it! This is for your own good!"*
>
> *[Carla]*

> *I have two scissors: my wife and my daughter. (…) When we go dinner out, which is not very common, but first thing they say is: "Be careful with what you eat!" Yes, yes, they help me. My daughter always gets the pills I am going to take.*
>
> *[Miguel]*

3.3 | Group 3. Narrative of disruption

3.3.1 | Dealing with the diagnosis

Interviewees tend to recall the diagnosis as a disruptive moment, after which they become self-aware of being at risk. António, for example, describes such a moment as an emotional roller-coaster that caused panic, anxiety and uncertainty:

> *After being diagnosed, I felt so bad, I dealt very bad with the news. Never nobody warned me for this! For 3 months, [I felt] panic, anxiety, (…) I thought I was going to die! (…) Being diagnosed with diabetes type 2 at 36, 37 years, is too scary! (…). It was a stone falling on my head.*
>
> *[António]*

They display understanding of health information and use technical language, as illustrated by Nuno's explanation of how the diagnosis of diabetes is done:

> *I don't know if you know, but a diagnosis of diabetes is made through routine glycemic level control, if it is higher than that cut off point. Probably with all prevention programmes, that will change in the future, but now it is done like this.*
>
> *[Nuno]*

After the diagnosis, patients search for detailed information about diabetes in several sources. This behaviour is described as having facilitated the acceptance of diabetes and the return to normalisation through a "restitution narrative"—when they assimilate and adapt their routines to their condition:

> *At the time [of diagnosis], I was reassured by the doctor and I started the medication. Gradually I started to be interested [in knowing more about diabetes]. I studied diabetes, went to conferences, read papers. I tried to find solutions, it was not easy for me to deal with this. Because I didn't want to depend on a medication for the rest of my life. Gradually, I accepted it better.*
>
> *[João]*

> *I was not shocked with the diagnosis. I was shocked that the doctor did not speak about it! I mean, the context (…) I felt that for every question I have asked (in the diagnosis consultation), he (the doctor) did not like that I asked. So, I manage the situation and I look for another doctor (outside public service) to have a counterpoint.*
>
> *[Nuno]*

3.3.2 | Self-management skills

Interviewees tend to feel confident to manage diabetes autonomously, and believe that suitable lifestyles, namely exercise and diet, will be enough to manage diabetes in the future. Compliance with medication is mentioned as the first recommendation to be "avoided". Patients' worries about side effects of medication lead them to seek the glycemic control only through diet and exercise, placing the responsibility to avoid medication in themselves. If they do not succeed in controlling glycemic levels without medication, it is only then that they take it:

> *My yearning is to be able to reach the moment when just with a healthy diet and this lifestyle (daily exercise) I will no longer need medication, and I almost can do that. I don't want to be dependent on medication, it makes me feel bad. Also, I am aware of the real costs of this kind of medication, and I think that the way things go, one day I will have to pay that totally by myself, because there will be no public money to support this. At that moment, I surely don't want be dependent on this medication, it is too expensive.*
>
> *[João]*

> *Because I studied the condition … I saw my levels and I'm really on the borderline of being non-diabetic, it is such a tiny difference. (…) I prefer that someone tells me: "go do exercise, go upstairs and down" than "take this medication". I know that some doctors prefer that way. So, the main responsibility was and is mine.*
>
> *[Nuno]*

3.3.3 | Health literacy mediators

This group has the smallest number of health literacy mediators: first, family doctor and Internet; second, private family doctor; and lastly, family members (Figure 1—Group 3). The use of such sources of information other than health professionals tends to lead into a critical literacy and to finding alternative solutions for improving their health condition:

> *I have a very scientific approach when I'm studying something, I go deep into the subject. And I did a 3 months diary about my daily diet. I already have done it for my mother, when she had Alzheimer's. (…) It helped my mother, and know it helps me to control diabetes (without medication). It's a way of controlling and trying to figure out what it is the best way to control glucose levels.*
>
> *[Nuno]*

These interviewees feel the need of studying to disseminate information and advice to others, specifically the closest, as Nuno states:

> *I am the type of person who likes to go deeper, to retain and summarise the more important, in order to spread it through my children and family members: "look, this is my experience … take care" something like that.*
>
> *[Nuno]*

Additionally, worries with diet determine major lifestyle changes, such as becoming vegetarian and even organising workshops on vegetarian diet, under the assumption that it is beneficial for diabetes. In addition, vegetarianism is seen as a way of helping healthy people, who might be at risk from becoming diabetic, to have a healthier lifestyle:

> *I believe it is better not only for diabetes but for a healthy lifestyle.*
>
> *[Margarida]*

4 | DISCUSSION

This study demonstrates that exploring meanings given to diagnosis, identifying health mediators and analysing the structure of social networks, in particular shared practices and responsibilities, can contribute to understand the distributed nature of health literacy. The acknowledgement of the distributed nature of health literacy provides complementary information about the influence of social networks to a more sustainable patient-centred care. Moreover, our findings also determine that social networks act both as "systems of support" and as critical sponsors to diabetic's self-management, dimensions already discussed and recognised in previous studies (Foss et al., 2015; Rogers et al., 2011; Vassilev et al., 2013).

Diagnosis of diabetes emerges as a critical starting point of the communication process of becoming a literate patient. The minimisation of diagnosis (Group 1) translates into resignation towards what are believed to be "inevitable" consequences of the diagnosis of diabetes and is more frequent among people with lower education levels, while disruption (Group 3) gives rise to navigate in the health system searching for alternatives (e.g. managing diabetes without medication, just through healthy lifestyles), being more common in persons with high levels of education. The narrative of empathy (Group 2) reflects the "good patient" (Jadad, 2003) whose attitude towards diagnosis appears as positively linked to the incentive to act according to the recommendations of health professionals, especially when prioritising medication. As Brown (1987, 1990, 1995) and Jutel (2011) argued,

> exploring the perspectives and experiences associated with a diagnosis provides an important insight into how people understand and recognise disease, illness and health, shaping their knowledge and practices regarding patient–doctor interaction, pharmaceuticalisation, self-management and disease acceptance.

Those who tend to minimise diagnosis rely on a broader network of mediators with a high number of interactions, making the management of diabetes more complex. In this context, the disclaimer of responsibility for self-management and inconsistent information or conflicting advice are more likely to occur, specially within mediators with low levels of health literacy, potentially influencing the health outcomes of the patient (Garcia, Espinoza, Lichtenstein, & Hazuda, 2013; Yuen, Knight, Ricciardelli, & Burney, 2016). It is then important to articulate the tapestry that composes this frame of different skills by considering the distribution of responsibilities among all the mediators beyond the emphasis on individual patient's responsibility. Benefits are to be expected when people have health mediators and adequate social support to the management of type 2 diabetes (American Diabetes Association, 2014; Fisher et al., 2012; Rothschild et al., 2014; Thom et al., 2013; Gagliardino et al., 2013; Smith et al., 2011; Dale, Williams, & Bowyer, 2012; Zhang, Yang, Sun, Fisher, & Sun, 2016; Finset, 2015), according to their own needs and life circumstances: individuals in Group 1 (narrative of minimisation) need "basic" health information, helping directly in daily tasks, while those belonging to Group 2 (narrative of empathy) need help to understand health information and receive emotional support to pursue healthy behaviours, such as helping them pursue a healthy diet, as a most meaningful simple act of caring; and Group 3 (narrative of disruption) need to have access to a more detailed and formal information about diabetes in order to prevent the emotional roller-coaster that diagnosis of diabetes might otherwise lead to.

The DHL of each individual may reflect a blend of their illness identity, as a result of life trajectories and consequent meanings given to diagnosis, unveiled in the restitutive narratives. These narratives are the result of accepting, mastering or adapting illness to normal life course (Finset, 2015), as well as a synonym of the burden that self-management practices might represent for patients and also, as Sav et al. (2013) noted, to their careers.

The complexity and heterogeneity of the DHL can be teased apart by examining how people deal with diagnosis and how the support from all mediators involved in the network interact with their self-management skills. Partially consistent with results of other study that focus the influence of social networks and social support in chronic conditions self-care (Gunn, Seers, Posner, & Coates, 2012; Koetsenruijter et al., 2016), our study has shown DHL to be significantly important to assure a proper illness self-management, filling the gap that individual health literacy leaves open.

These findings are, however, limited by the sample size and the cross-sectional nature of the study design, not being able to assess behaviour changes through time, as well as gendered narratives of the experience of care or self-management of diabetes. Recall bias may have also influenced interviewees' narratives, as patients recalled experiences extending as far back as to diagnosis, from 30 years ago to 2 years.

5 | CONCLUSION

Meanings given to diagnosis—disruption, empathy and minimisation—were associated, respectively, with a growing individual network of literacy mediators and shared practices of each patient, contributing to a deeper understanding of the distributed nature of health literacy. The influence of a network of family, friends, media and health professionals providing mainly informational support was particularly strong when patients had lower educational levels.

DHL can fill the gap left open by an emphasis on individual health literacy, showing that a strong, articulated and oriented network of health literacy mediators might compensate the adverse effects of low levels of literacy. To take into account the transfer of acquired skills and patient support by each social network would facilitate the encouragement of patient-centeredness and the understanding of clinical relationships partnerships.

5.1 | Implications for practice

This study shows how the involvement of multiple mediators in each individual networks contributes to different health literacy practices. It is necessary to create hybrid spaces for dialogue between them to activate empowered attitudes. For example, spaces should be constructed for patients to ask more questions and

participate in more informed health-decision-making discussions. Research on health systems that aim to develop new or improve on existing models, in order to make them more patient-centred, should give attention to patients' DHL rather than just emphasising individual health literacy capabilities. This implies giving particular attention to the way patients deal with diagnosis, identify the mediators and clarify the distribution of capabilities and responsibilities in the network.

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CONFLICTS OF INTEREST

No conflicts of interest are declared.

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4.2 Paper II. The role of distributed health literacy in asthma integrated care: a public medical context from Portugal

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RESEARCH AND THEORY

The Role of Distributed Health Literacy in Asthma Integrated Care: A Public Medical Context from Portugal

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Background: Improvements in asthma integrated care might be achieved through in-depth knowledge about how health literacy is dispersed through a group. This study intends to map out health literacy mediators (those who *makes his/her literacy skills available to others for them to accomplish specific literacy purposes)* and how they enable self-management skills in patients with asthma.
Methods: Twenty interviews were conducted in a Primary Care Center of Porto using the McGill Illness Narrative Interview. Data were thematically analyzed as case-based and process-tracing-oriented.
Results: Interviewees with a dense network of mediators revealed a low impact of asthma on their lives, dependence on primary care physician for instrumental support and dependence on family members to provide emotional/pragmatic support. Interviewees who relied on a restricted network of mediators (belonging to formal sources of health services and providing informational support) described episodes of crisis as disruptive and demonstrated a reactive approach to self-management skills.
Conclusions: The roles performed by core health mediators (health professionals, family/friends, media) in support of asthma management varied according to patients' narratives of minimization/disruption, connected to dense/restricted social networks. To clarify the boundaries of responsibility-shifting and to enrich support provided by formal sources of health services and peer education groups is needed.

Keywords: health mediators; health literacy; people-centred care; integrated care; asthma

Introduction

Therapeutics and asthma patient-centred care have advanced over the last two decades [1–4]. However, asthma is still often poorly managed [5, 6], with asthmatics having difficulties in access or use of health care and in adhering to treatment regimens [5], as well as lacking self-management skills [7, 8]. Asthma is still an important reason for hospital admission worldwide [9, 10] and causes considerable limitations on the lives of both patients and their families [11, 12]. These barriers pose significant direct and indirect economic costs and psychosocial burden [13], particularly evident in asthmatics with inadequate health literacy [14]. Instrumental and emotional support provided by robust social networks and informal caregivers is likely to overcome such barriers [15, 16] by assisting asthmatics in obtaining, processing, understanding and applying basic health information and services needed to make appropriate health decisions and meet daily self-management demands [17–19]. Improvements in asthma integrated care might thus be achieved through in-depth knowledge about how health literacy is dispersed through a group of individuals or a community is considered – distributed health literacy – as coined by Edwards et al. [20]. It is particular critical for health literacy interventions in communities to identify health mediators and their roles in an asthmatic's tasks related to health literacy, that is, anyone or anything which '*makes his, her or its literacy skills available to others, on a formal or informal basis, for them to accomplish specific literacy purposes*' [21], such as the use of regular inhaled preventive or prophylactic medication namely, help to quit smoking, motivation to practice physical exercise and lost weight, and help in avoiding professionals risk environments [22].

Pioneering case studies in India highlighted the influence of communities on health practices, showing for instance that sharing information and experiences among mothers living in the same village increased the probability of immunizing their children, with this factor being stronger correlated with childhood immunization rates rather than the individual literacy level of mothers [23, 24]. In fact, daily life occurs in circumstances where health-related decisions and behaviors are not made just by individuals but are powerfully influenced by family members, peers and/or community leaders [25, 26].

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Among patients living a long-term health condition, such as asthma, distributed health literacy emerges as a potential resource for managing one's health, communicating with health professionals and making health decisions [20]. This approach epitomizes the current worldwide movement towards integrated, people-centred health services [27], co-production of knowledge, shared care and shared governance for health sustaining the provision of tailored health services that aim to synchronize care both with and around the needs of service users, their families and the communities, meeting an individual's or group's specific characteristics within the context of their lives [27]. To map individuals and resources involved in patients' asthma management and exploring the properties of relations and ties between health mediators regarding density, range, boundedness, and homogeneity [28], it is essential to describe the exclusive forms, organization and composition of patients 'health networks' [27]. These networks are often important conduits for shared resources whose enhancement must also reflect the views of patients to certify that the healthcare services and health governance consider their beliefs, contexts and needs [29].

This study focuses on how asthmatics draw on their social network for support with health literacy-related tasks, mapping out health-literacy mediators for each individual, and how they enable self-management skills and knowledge about asthma.

Methods

This is a qualitative observational study conducted in Portugal, where the first National Asthma Control Program was established in 2000, aiming at improving skills and competences in the patients and their families [30]. In 2010, the only Portuguese National Asthma Survey – Inquérito Nacional sobre Asma (INAsma) estimated a prevalence of 'current asthma' (i.e. with symptoms in the last 12 months) in the Portuguese population of 6.8% (95% Confidence Interval 6.0–7.7); among these, 57% had the disease under control [31].

In Portugal, asthma access care is made through standard primary care, in medical appointments without standardized routines for asthma care (**Box 1**). Under the presence of a restrict number of clinical criteria, patients are referred to specialized allergy consultations in the hospitals. Almost half of the 225 hospitals located in Portugal are private (n = 111), being frequently used by people with higher socioeconomic status (SES) to treat asthma.

This study was carried out in a Family Health Unit located in an urban area in Porto District (Northern Portugal). From October 2014 to December 2015, a convenience sample of adults diagnosed with asthma, for more than one year, were invited by all health professionals working at this center (six primary care physicians and five nurses) to participate in the study after medical consultations (not necessarily related to asthma). In this center, 337 out of 10 361 users (including adults and

Box 1: Brief description of the Family Health Unit (USF) in the study

History and nature in the health system	· Reform of primary health care in Portugal 2005 – Constitution of USFs, coordinated by one of the five Health Center Clusters (ACeS). · 'Bottom-up' approach – self-organized teams of health professionals through voluntary applications to provide care in a particular geographic region (Ministry of Health, 2010). · Each team has autonomy in terms of technique-care and functional management and it is constituted by family doctors, nurses and clinical secretaries. · There are 483 USFs in Portugal, with 8945 professionals (*data from 5th May 2017*). · Each doctor working on the USF of this case study provide primary care to 1800 patients (legal max. 1900). · Public primary health care units are the first contact point of the citizen with the health system.
Provision of asthma care – guidelines	· **Content of asthma care:** Total control of symptoms; reduction of risks of crisis; reduction of progressive bronchial obstruction and adverse effects of medication; diagnosis and control of comorbidities; promote therapeutic adherence; correct use of inhalers; improvement of quality of life; and support for having a daily life without limitations. · **Role of family doctor:** Guarantee that all asthmatics get an adequate and personalized healthcare; raise awareness and provide essential information about the disease to all citizens; promote therapeutic adherence and reinforce the importance of asthmatic empowerment and family support in asthma management; longitudinal relationship with patients, continuous care; reevaluate an asthma without control and refer these cases to a specialist in pulmonology and immunoallergology.

children) had been diagnosed with asthma (Data from 2015, provided by the Primary Care Center). Invitations were made during the days the researcher went to the center. Participants were purposively sampled to include patients with a diagnosis of asthma in childhood and in adulthood, under the assumption that early age asthma onset might distinguish different asthma phenotypes [32], which may be related to persistence and severity of disease and directly linked to different self-management experiences. Heterogeneity sampling was used for maximum variation of views and experiences regarding adherence to asthma self-management, until the point when no new, significant data emerged from data analysis – that is, the point of theoretical saturation [33], possible to achieve with at least 15 interviews in nonprobabilistic samples [34]. All the 20 invitees accepted to participate, and 4 asked to reschedule the interview for another day of their convenience.

Data were collected based on the McGill Illness Narrative Interview (MINI), previously applied in a Portuguese study about health knowledge of people with asthma and breast cancer [35]. MINI is a semi-structured ethnographic interview schedule, intended to produce narratives and status of health knowledge [36], comprising the next sections: 1) Initial Narrative – purposefully unstructured, letting interviewees to tell their story freely; 2) Prototypes – structured, intending to elicit narratives on typical experience of self and others; 3) Explanatory models – causal type of reasoning; 4) Help seeking and service utilization – interviewee experience with health services and treatments; 5) Impact of illness – explore if and how patients believe the illness has led to changes in their identity and way of life since its diagnosis. For the purposes of this paper, two extra topic questions were addressed to explore the role of health mediators: "Do you usually go accompanied to the medical visits (if yes, with whom)? If we ask you to choose someone to help you in a health-related issue, who would you choose and why?" (it was stated to the patients that they could mention more than one person).

Interviews were conducted by the first author in a reserved room at the Primary Care Center, and lasted 50 minutes on average. All were taped, professionally transcribed verbatim, and checked for accuracy.

Data were thematically analyzed [37] as case-based and process-tracing-oriented, by the first author, with the assistance of NVivo 10 (QSR International, USA, 2013). Process-tracing was accomplished through coding each interview to identify categories associated with the following previously defined themes of interest [38], incorporating constant comparison of the coded interviews, and exploration of deviant cases: 1) 'dealing with an asthma diagnosis', which explored attitudes, trajectories and levels of awareness and knowledge about asthma; 2) 'self-management skills', when discourses pointed to access to health services and how participants manage medication, and potential triggers of asthma crisis; and 3) 'health literacy mediators', where the interviewees mentioned sources of support (formal, informal or other) and types of support (pragmatic, informational and emotional). The development was discussed by three of the authors. Disagreement was solved by continuous and iterative joint discussion until consensus could be reached.

The 20 patients selected consisted of 17 women (12 elementary educational level, 3 high education level and 2 secondary educational level) and 3 men (2 elementary educational level and 1 secondary educational level). Their ages ranged from 21 to 70 years old. The diagnosis at adulthood length ranged from one to 20 years and five were diagnosed in childhood (see **Table 1**).

All participants formalized their collaboration through a written informed consent. Ethical approval was granted by the Research Ethics Committee of the Institute of Public Health of the University of Porto.

Results

Two distinct narratives emerged from data analysis – the narrative of minimization and the narrative of disruption. The narrative of minimization was enacted by interviewees who had a dense network of health literacy mediators. These patients claimed low impact of asthma on their lives and daily routines, easy control of symptoms and avoidance of major crisis, and dependence on their primary care physician for instrumental support and on close family members with asthma to provide emotional and pragmatic support with medication and alert them to situations that might trigger an asthma attack. A narrative of disruption was enacted by interviewees who relied on a restricted network of core health mediators made up of formal sources of health services (clinical interaction or online) used mainly to provide informational support. They described episodes of crisis as highly disruptive, their difficulties in controlling crises and their feelings of stigma. These patients tended to hide asthma and to look for alternative and complementary solutions to control anxiety, demonstrating a reactive approach to asthma management. Results are illustrated by direct anonymized quotes, translated by the authors, drawn from the interviews. These are presented in **Table 2** (narrative of minimization) and **Table 3** (narrative of disruption).

Narrative of minimization

Dealing with an asthma diagnosis

Asthma was frequently mentioned as a condition that 'is in the family' and, consequently, a diagnosis of asthma was not a surprise [1.1a]. Most interviewees had close family members with asthma, whether parents, children, siblings or partners. Diagnosis emerged as a map for steps ahead and the validation of previous symptoms, and signaling the end of suffering now that treatment became possible [1.1b].

Interviewees suggested that the degree of familiarity with asthma determined how people cope with such a condition. By comparing asthma severity among relatives, interviewees tended to report feeling reassured about having a less severe asthma [1.1c]. The diagnostic consultation emerged as a landmark, with interviewees recalling the exact words of the primary care physician, mentioning

Table 2: Representative quotes of the main themes – narrative of minimization.

1.1 Dealing with an asthma diagnosis (low impact; family condition; importance of the diagnostic consultation)
[1.1a] Elsa: "I was not surprised (when diagnosed with asthma) … My son has asthma since a child, my father also had it. It is in the family."
[1.1b] Júlia: "I didn't worry (about asthma diagnosis). Because I was always feeling bad (…) and then I saw the problem solved."
[1.1c] Filipa: "I already knew that he [family doctor] was also asthmatic (…) and he said: "don't be afraid, because when I was in college I already had asthma and I am still around." To have heard this was reassuring."
[1.1d] Filipa: "I already knew that he [family doctor] was also asthmatic (…) he said to me: 'don't be afraid, because when I was in college I already had asthma and I am still around.'"
1.2 Self-management skills (avoidance of major crises; control of symptoms by SOS medication)
[1.2a] Elsa: "I know that if I am in some bad environment, with smells, of course I will be attacked. But I know what to do (SOS medication)."
[1.2b] Júlia: "It is more at night that I have more asthma, (…) and when I am attacked, I take my SOS pump and I immediately get better."
[1.2c] Maria: "My doctor prescribed me a medication, and I started doing it. But then, my mother-in-law, who suffers from bronchitis and used to take the same medication, told me: 'don't take that, then you get used to it and can't walk anymore': So I stopped. But then I went to a pharmacy and he (pharmacist) told me to do it, and I did; but later another pharmacist, in another pharmacy, told me to leave it. And now I don't take it."
1.3 Health literacy mediators (dense network)
1.3.1 Family and friends (close family members; emotional and pragmatic support)
[1.3.1a] Filipa: "The medication was the same as my husband, and sometimes we shared. (…) When we go on vacations, his last question before leaving home (…) is if I have brought the pumps."
[1.3.1b] Manuela: "I went there 42 because they (siblings) told me that he (a doctor) was great! (…) He did an exam that nobody here in Portugal told me to do."
[1.3.1c] Graça: "If I'm having a crisis, (…) my daughters (…) know exactly what to do: one of them goes right away search for my inhaler/pump. They know that I always carry one in my bag or in my pocket."
[1.3.1d] João: "If I am a little 'attacked' my wife immediately says: "you will have a crisis!". (…) She always ensures that I take it (medication)."
[1.3.1e] João: "Once, my friends and I went to ride in karts. The building, completely indoor, was full of smoke from the karts. I felt bad, completely short of breath (…) My friends came with me outside, to breathe."
[1.3.1f] Filipa: "I have friends calling me, saying: "So, did you go to that doctor?" (…) They worry."
1.3.2 Health professionals (PCP; instrumental support)
[1.3.2a] Sebastião: "I go there (primary care center) often (…) usually I have two consultations a year."
[1.3.2b] Ema: "I don't like to go to different doctors, because they all say different things."
[1.3.2c] Cristina: "My doctor is great. She really worries about us; we can feel it is genuine. She has a very close relationship with me, my son… I already told my sister [also asthmatic] she should move to this primary care center and be patient of my doctor."
1.3.3 Media (not always reliable)
[1.3.3a] Cristina: "I also go to the internet (…), but I think that sometimes it is bad, because they give opinions, but they are not experts."
[1.3.3b] Graça: "If people say things differently from the doctors, it is wrong, I don't trust it. Not everybody can write about this (asthma); it must be a doctor."

Narrative of disruption

Dealing with an asthma diagnosis

Participants mentioned the highly disruptive impact of asthma in everyday life, highlighting changes in the way they "see life" [2.1a]. They mentioned "upsetting" limitations when practicing sport or participating in other leisure activities [2.1b; 2.1c] and feelings of stigma associated with others' negative reactions upon witnessing episodes of crises [2.1d].

Interviewees reported several attempts to preserve a public image in which asthma is kept hidden and symptoms are less obvious. Elsa, for example, recognized that her son (also asthmatic) wanted to hide asthma from his colleagues, and never took medication to school [2.1e]. In some cases, interviewees have trouble understanding why asthma appeared for them but not to their friends or partners who engaged in risk behaviors for asthma (e.g. smoking) [2.1f].

Self-management skills

Interviewees revealed a reactive approach to asthma management, feeling the need to address their asthma only when symptoms increased or significantly impacted their daily life. Taking preventive medication was not maintained, alternative and complementary solutions and coping strategies were used to control anxiety, as for instance, through

Table 3: Representative quotes of the main themes – narrative of disruption.

2.1 Dealing with an asthma diagnosis (disruptive impact; feelings of stigma; to hide asthma)
[2.1a] Isabel: "Asthma did change my life and the way I see life... At least when I'm attacked."
[2.1b] António: "When practicing swing, soccer, running, and other sports, it (asthma) does not allow us to be as resistant as other persons."
[2.1c] Rita: "I want to do things, but I'm not able to do so (...) and people sometimes do not understand. Sometimes I feel people are saying: 'she is faking it.' (...) It is very upsetting."
[2.1d] Idalina: "It's hard! People stay disgusted, with a weird face (when seeing an asthma attack)."
[2.1e] Isabel: "He (participant's son, also asthmatic) does not take it (the pump) to school (...) (because) he does not like to say he has asthma, since very little."
[2.1f] Laura: "Causes? I think it was from tobacco (her husband smokes). And I don't smoke! Do you believe? It is so frustrating."
2.2 Self-management skills (reactive approach; alternative solutions; feelings of personal guilt)
[2.2a] Rita: "I feel anxious and in panic [when having a crisis]. (...) Oh my God, if I use the pump and it does not work, I panic, and I just pray to pass."
[2.2b] Anabela: "Yes, I have searched for other options, such as, acupuncture. And it was good, I felt some benefits."
[2.2c] Helena: "I have the pump. My doctor told me to use it every day, but I only do it once in a while. Because I like to read patient information leaflet, and if everybody read that, people would not take medications. Because what it is written there, it really might happen."
[2.2d] Anabela: "I don't know, maybe I've been lazy...The pediatrician of my son told me my medication (for asthma) was totally outdated and I should start a new treatment. I really have to convince myself and have a medical consultation about this."
[2.2e] Isabel: "People say that the beach is bad for the lungs, and when I'm attacked I don't go to the beach. I'm afraid."
[2.2f] António: "The last couple of years, (...) I take medication more regularly (...) and I go to the emergency rooms quite often (...) It already happened go to the hospital twice a month."
[2.2g] Anabela: "Usually, when I'm attacked I take Ventilan in SOS, and it is effective. However, since last month I have been taking Ventilan 3 to 4 times a day, and it is not working, I still have the symptoms."
2.3 Health literacy mediators (restricted network)
2.3.1 Health professionals (PCP; communication issues)
[2.3.1a] António: "Sometimes I need to know something quite specific – for instance why my crisis are more regular – and I just ask to the doctor. But actually, nowadays, we don't need to come here to know something, I go online or to the medical leaflets."
[2.3.1b] Rita: "I'm from the opinion that explaining things helps a lot. For instance, last month I went to do some exams at the hospital, and during the exam I asked a lot of things to the nurse. She was very nice, and answered me. But her colleague told me: 'you don't need to know! It's the doctor that must know everything!'. But that's wrong. We are the patients, we should know."
[2.3.1c] Ema: "I think the hardest part is the language, I think it is. Because doctors speak for each other's, not for the patient. Once I was hospitalized, and a group of doctors just came to my room, they spoke for each other's, and I didn't understand a thing."
2.3.2 Media (Internet; not reliable)
[2.3.2a] Anabela: "Once I was having cramps, so I went online to search something about what was causing me that, and read that people with asthma tend to have more cramps than usual. But I don't know if it is true, I only find that in one website. No where else."
2.3.3 Family and friends (lack of support)
[2.3.3a] Helena: "My husband usually tells me: 'Calm down'! (...) When he tells me that, I got much worse. Oh my God, I can't hear that. (...) I know that my husband just wants to help me, but I can't avoid this."
[2.3.3b] Idalina: "Nobody helps or anything. I am the one who have to help the others."

praying [2.2a] or acupuncture [2.2b]. Reading the patient information leaflet was one of the main reasons why participants showed reluctance adhering to medication [2.2c].

Some interviewees expressed feelings of personal guilt stating they did not make enough income to improve their asthma status [2.2d]. Lack of knowing how to recognize the triggers of asthma also led to limiting their life in 'asthma periods', such as avoiding going to the beach [2.2e]. Experiencing asthma crises and not being able to control it led to more visits to the emergency rooms [2.2f], as well as to an excessive intake of quick relief medication [2.2 g].

Health literacy mediators

This group of interviewees had a restricted network of core mediators (**Figure 1**). It included experts working on the healthcare system (the primary care physician, lung specialists), with whom they had strong ties, and the media (internet and health advice hotline *Saúde 24*), making up weak ties, providing informational support such as access

Table 3: Representative quotes of the main themes – narrative of disruption.

2.1 Dealing with an asthma diagnosis (disruptive impact; feelings of stigma; to hide asthma)
[2.1a] Isabel: "Asthma did change my life and the way I see life... At least when I'm attacked."
[2.1b] António: "When practicing swing, soccer, running, and other sports, it (asthma) does not allow us to be as resistant as other persons."
[2.1c] Rita: "I want to do things, but I'm not able to do so (...) and people sometimes do not understand. Sometimes I feel people are saying: 'she is faking it.' (...) It is very upsetting."
[2.1d] Idalina: "It's hard! People stay disgusted, with a weird face (when seeing an asthma attack)."
[2.1e] Isabel: "He (participant's son, also asthmatic) does not take it (the pump) to school (...) (because) he does not like to say he has asthma, since very little."
[2.1f] Laura: "Causes? I think it was from tobacco (her husband smokes). And I don't smoke! Do you believe? It is so frustrating."
2.2 Self-management skills (reactive approach; alternative solutions; feelings of personal guilt)
[2.2a] Rita: "I feel anxious and in panic [when having a crisis]. (...) Oh my God, if I use the pump and it does not work, I panic, and I just pray to pass."
[2.2b] Anabela: "Yes, I have searched for other options, such as, acupuncture. And it was good, I felt some benefits."
[2.2c] Helena: "I have the pump. My doctor told me to use it every day, but I only do it once in a while. Because I like to read patient information leaflet, and if everybody read that, people would not take medications. Because what it is written there, it really might happen."
[2.2d] Anabela: "I don't know, maybe I've been lazy...The pediatrician of my son told me my medication (for asthma) was totally outdated and I should start a new treatment. I really have to convince myself and have a medical consultation about this."
[2.2e] Isabel: "People say that the beach is bad for the lungs, and when I'm attacked I don't go to the beach. I'm afraid."
[2.2f] António: "The last couple of years, (...) I take medication more regularly (...) and I go to the emergency rooms quite often (...) It already happened go to the hospital twice a month."
[2.2g] Anabela: "Usually, when I'm attacked I take Ventilan in SOS, and it is effective. However, since last month I have been taking Ventilan 3 to 4 times a day, and it is not working, I still have the symptoms."
2.3 Health literacy mediators (restricted network)
2.3.1 Health professionals (PCP; communication issues)
[2.3.1a] António: "Sometimes I need to know something quite specific – for instance why my crisis are more regular – and I just ask to the doctor. But actually, nowadays, we don't need to come here to know something, I go online or to the medical leaflets."
[2.3.1b] Rita: "I'm from the opinion that explaining things helps a lot. For instance, last month I went to do some exams at the hospital, and during the exam I asked a lot of things to the nurse. She was very nice, and answered me. But her colleague told me: 'you don't need to know! It's the doctor that must know everything!'. But that's wrong. We are the patients, we should know."
[2.3.1c] Ema: "I think the hardest part is the language, I think it is. Because doctors speak for each other's, not for the patient. Once I was hospitalized, and a group of doctors just came to my room, they spoke for each other's, and I didn't understand a thing."
2.3.2 Media (Internet; not reliable)
[2.3.2a] Anabela: "Once I was having cramps, so I went online to search something about what was causing me that, and read that people with asthma tend to have more cramps than usual. But I don't know if it is true, I only find that in one website. No where else."
2.3.3 Family and friends (lack of support)
[2.3.3a] Helena: "My husband usually tells me: 'Calm down'! (...) When he tells me that, I got much worse. Oh my God, I can't hear that. (...) I know that my husband just wants to help me, but I can't avoid this."
[2.3.3b] Idalina: "Nobody helps or anything. I am the one who have to help the others."

praying [2.2a] or acupuncture [2.2b]. Reading the patient information leaflet was one of the main reasons why participants showed reluctance adhering to medication [2.2c].

Some interviewees expressed feelings of personal guilt stating they did not make enough income to improve their asthma status [2.2d]. Lack of knowing how to recognize the triggers of asthma also led to limiting their life in 'asthma periods', such as avoiding going to the beach [2.2e]. Experiencing asthma crises and not being able to control it led to more visits to the emergency rooms [2.2f], as well as to an excessive intake of quick relief medication [2.2 g].

Health literacy mediators

This group of interviewees had a restricted network of core mediators (**Figure 1**). It included experts working on the healthcare system (the primary care physician, lung specialists), with whom they had strong ties, and the media (internet and health advice hotline *Saúde 24*), making up weak ties, providing informational support such as access

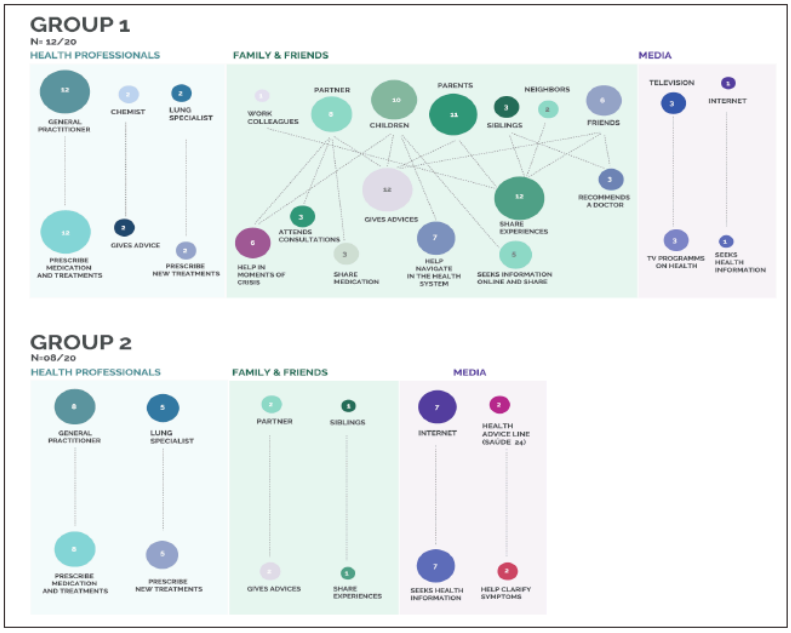

Figure 1: Map of health literacy mediators and practices according to awareness narratives.
[1] Circles are the frequency that each mediator was mentioned and lines are the association to different health literacy practices.

to specialized health information [2.3.1a]. Nonetheless, the communication with health professionals was not always described as effective, which limited patient engagement and a more active participation on treatment [2.3.1b; 2.3.1c]. Commonly, when people felt isolated symptoms – which in their opinion did not justify a visit to the doctor – they tended to search online for a solution, but were usually skeptical about the information available [2.3.2a].

Family members who were emotionally close rarely emerged as health mediators and they were not always successful in providing support [2.3.3a]. That gave rise to patients feeling that they lacked support to help manage the condition while, in the narratives of some interviewees, they assumed the responsibility of helping the others [2.3.3b].

Discussion

This study reveals several features that can be useful in integrated people-centred health services for asthma. It helps in clarify responsibility-shifting between main health mediators, enabling effective collaboration between health professionals (in particular the primary care physician and lung specialists), family and friends, and media (especially the Internet), through the identification of their roles and level of centrality in supporting asthma management in relation to two main awareness narratives – minimization versus disruption. These narratives are characterized by distinct reactions to diagnosis – low impact versus disruption/feelings of stigma, different approaches to self-management skills – control versus reactive/alternative solutions, and dependence on diverse types of support – instrumental by primary care physician /pragmatic and emotional by relatives within dense networks versus informational by primary care physician and Internet within restricted networks. The ties established with each mediator are stronger when interactions are more frequent (intensity of ties), when it is easier to make contacts (dispersion), and when the information is comprehensible, consistent and reliable. This finding draws attention to the importance of exploring interactional factors, in particular patient- primary care physician relationships, to understand patient's distributed health literacy. Considering that patients showed they were not confident in relying and trusting in information found online, this feature also supports the need to assess the quality of asthma-related websites, in a context where improving the quality of health-related websites have the potential to improve health literacy of general population [39]. Finally, this study draws attention to the challenge of care for people with chronic complex needs and how care should be addressed at the patient in his/her social network and local community, aiming at understanding how sharing responsibilities works and how concepts such as 'engaging the community' and 'distributed health literacy' explain compliance of patients in care.

A narrative of minimization tended to be activated by those who 'accept' the identity of 'asthmatic', which contrasts with the disruptive narrative of 'deniers'. These identities have been previously identified by Adams [40] among patients with asthma, not disclosing any particular link between attitudes towards asthma and SES. Narratives correspond to acceptance or rejection of their condition and are associated with different attitudes towards medication, disease management and coping strategies. What this study adds to the literature is the idea that these identities are connected to different configurations of social networks of each individual, which highlights the

Box 2: Recommendations for an USF with Integrated Asthma Care Provision

1. Annual reassessment of the health status of the patient, focusing on the frequency of asthma symptoms and update medical prescriptions (considering the dosage, duration and adverse effects of the treatment and medication).
2. To explore reactions to diagnosis (acceptance or rejection) and to identify health mediators in an asthmatic's tasks.
3. To clarify responsibility-shifting between main health mediators, enabling effective collaboration between them through the creation of hybrid spaces for dialogue.
4. Personalized educational interventions to help acceptance and minimize negative impacts that psychosocial difficulties might have on self-management strategies.
5. To enrich support provided by peers' education groups, especially on the transition periods (from childhood to adolescence and adulthood) and for those without asthma in their close family.
6. To assess the quality of asthma-related websites.

importance of analyzing patients' narratives to trace the tapestry that compose them. Core network of health mediators provided most of health literacy competencies (e.g. by giving advice, preventing exposure to certain environments or preventing symptoms, helping in moments of crisis and intake of quick relief medication, sharing experiences, helping with coping strategies, understanding and obtaining information about asthma, seeking online information, or recommending a doctor). Thus, planning feasible asthma self-management regimens needs us to approach health literacy as a distributed attribute and not exclusively individual [41, 42]. Improving interactions between health mediators while clarifying the distribution of responsibilities among those involved in shared health literacy practices would create health benefits [43] that may also extend to the social domain [44].

The fact that participants did not make reference to structural support provided by peers who were non-relatives, such as friends with asthma and family members without asthma – who have reported difficulties in advising asthmatics – points to the need of promoting education groups with peers and family members, especially for those without asthma in their close family. That is typically the case of those with a disruptive narrative. In fact, transgenerational paths of chronic illness minimize the negative impacts that psychosocial difficulties might have on self-management strategies [45, 46]. Additionally, through the analysis of the coping strategies and resilience patterns of each patient, a collective understanding of illness susceptibility and its effects in lessening the disruptive potential towards one's biography might be achieved [47, 48]. It is possible that by relying on these models people may employ adequate self-management and effectively integrate of asthma into their lives and identity [49, 50]. These prototypes may also help turn disruptive assertions towards normalcy, in the form of "restitution narratives", which prevent the threat of identity discontinuity imposed by chronic illness [51]. What makes this proposal particularly relevant is the existence of the narrative of disruption in asthmatics diagnosed in childhood. That contradicts the assumption that diagnosis in childhood would raise confidence over time. Those diagnosed since childhood instead, show some 'saturation' regarding asthma and lower adherence to medication and treatments [52]. This observation underlines the importance of patient counseling and peers education groups, specifically on the transition periods (from childhood to adolescence and adulthood) when compliance tends to fail more due to patient-related determinants [53, 54].

This study is not without limitations and some issues that became apparent were the gendered narratives of the experience of care of self-management, as well as the limitation of our sample size, and the cross-sectional nature of the study design. Recall bias may also had influenced interviewees' narratives, as patients recalled experiences extending as far back as to diagnosis, for some interviewees, since childhood.

In conclusion, this study stresses the need for addressing distributed health literacy through narratives that show patients' awareness, in order to identify the diversity of roles performed by core health mediators in support for asthma management. Findings helped to develop recommendations for integrated asthma care (**Box 2**) in particular by clarifying the boundaries of responsibility-shifting between health mediators and patients though two main viewpoints: firstly, identifying networks and types of support on asthma daily management; and secondly, exploring the interactional factors to understand patient attitudes towards asthma. However, future research is needed to assess how networks configurations change over time and how types of support are affected through life-course.

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Competing Interests

The authors have no competing interests to declare.

Author Contribution

All authors took part of the data analysis and were involved in the manuscript preparation.

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4.3 Paper III. Patients' perceptions of family engagement in health information practices: influences in the self-management of asthma

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(Under review)

Patients' perceptions of family engagement in health information practices: influences in the self-management of asthma

Abstract

Background: Involving patients and family members in care is a growing area of research and practice, as more family members are expressing the desire to participate as constituents of the patient care team. In this study we aim to identify patients' perceptions of family participation in asthma self-management and health information behavior.

Methods: Semi-structured interviews with 35 patients with asthma were conducted at the Immunoallergology wards of both a central public Hospital and a private Hospital, in Porto, Portugal. Data was collected through the McGill Illness Narrative Interview. Interviews were thematically analyzed as case-based and process-tracing-oriented.

Results: Asthma in the family appeared as a major determinant of two profiles of asthmatics: Group 1 (n= 23/35), asthmatics are 'non-seekers' of health information, asthma is part of family history, and patients revealed easy adaptation to illness in everyday life, although feeling difficulties to control it, given the severity of asthma; and Group 2 (n=12/35), asthmatics are 'seekers', without asthma in the family and experience of illness brought limitations to everyday life, raising questions of bafflement (*Why me*?) and control (*What can be done*?).

Conclusions: Patients with asthma in the family tend to better accept asthma but need basic information for daily management. Patients without asthma in the family, tend to deny the condition and need more emotional support to cope with it. Family should be seen as relationships of shared knowledge and decision making, and how they experience the disease should be taken into account by health professionals.

Keywords: Health Communication; Health Information; Patient-Centered Care; Family Engagement; Asthma Self-management.

1. Introduction

International strategies recommended by Global Initiative for Asthma [1], as well as National Health Portuguese System specific guidelines and recommendations, support in effective clinical management [2]. However, despite the established treatment guidelines, many patients still experience persistent symptoms and, thus, poor disease control [3]. Asthma is still poorly managed, resulting in significant direct and indirect economic costs and psychological burden [4], causing considerable limitations on lives of both patients and their families [5, 6]. The Chronic Care Model and the World Health Organization's Innovative

Care for Chronic Conditions highlighted the need for more patient-centered care, and self-management and decision support for people with chronic conditions [7, 8], taking into account patients and families involvement in chronic health care management and health information seeking [9-11].

To promote synergies between patients' and their sources of health information, it is important to understand how experiences of health are constructed, whether if through knowledge acquired in daily interactions, when a health problem occurs or even through media use [12,13]. When exploring these dynamics, it should be taken into account the analysis of how health information seeking practices online are intertwined with people's offline experience of health and family health history [9, 10]. Informal social support, and more specifically, patients and families, are coping with day-by-day course that encompasses many individual episodes and events, placing higher trust in health information from family members [13]. Therefore, informal social support is important in a wide way that new forms of communication expertise might emerge and give shape to what is still a grey zone of knowledge and practice.

The currently broadly used concept of 'informed choice' is an indicator of the sense of empowerment nowadays experienced by (and expected of) patients, with access to a wide range of health information - supporting the idea of the expansion of medical knowledge via new technologies, namely trough Internet [14]. In the last decade, some studies [15,16], focused in determining if patients proactively seek information on their own to obtain answers, pursuing better quality of life, or (and) driven by the fact that information from traditional sources does not always meet their needs. The presence of the 'informed patient' in health information landscapes is a notion sustained in medical sociology through the concept of the "reflexive consumer" [17] of health information, partially a result of the process of patient empowerment [18, 19]. The basis of the common definition of empowerment within health promotion is derived from the Ottawa Charter assuming that it enables people to 'increase control over, and to improve their health'. Individuals may learn about a health topic by multiple means and paths. Either through a casual or intentional exposure to information, people are likely to come across health information in their routine use of media or in conversations with people in their networks, namely family members [20-22]. For instance, other studies [23, 24] suggest that "families often create the practical, social and emotional context for self-care, making it easier or harder for patients to achieve their health and behavior goals." As Piette [24] states, "The next advance we need in the current century is the recognition that for many patients, 'self' management is a misnomer, since their disease care is actually shared by their family and broader

social network." Several studies have explored problems associated with family influences in self-care and flow of health information, many of them concerned with adolescents and their parents or couples [25-27]. This study is part of a larger project named *Evaluating the State of Public Knowledge in Health Information in Portugal*, aimed at designing a strategy and tools for assessing knowledge on health of the Portuguese population, including asthma. The disease is a universal health problem, and the number of affected persons is estimated at 300 million worldwide [1]. Asthma affects 6.8% of the Portuguese population [28]. Lack of self-management skills, especially failure to adhere to treatment regimens, is still prevalent and meets some of the factors commonly drawn on to explain poor outcomes in asthma care [29-31].

Our objective was to identify patients' perceptions of family participation in asthma management, specifically in terms of health information seeking behavior, in patients living with mild to severe asthma.

2. Methods

This is a qualitative observational study conducted in Portugal. This study was carried out in Immunoallergology wards of both a central public Hospital (HSJ) and a private Hospital (CUF), located in an urban area in Porto District (Northern Portugal). From January 2012 to January 2013, a purposive sampling of thirty-five patients with a diagnosis of mild to severe asthma, for more than one year, were interviewed. In Portugal, asthma access care is made through standard primary care. Only under the presence of a restrict number of clinical criteria, patients are referred to specialized allergy consultations in the hospitals - these are the patients from are sample. The research team met with the clinicians from Immunoallergology Department of HSJ and it was decided that patients would be selected and invited by doctors in the days the researcher went to the Hospital. Heterogeneity sampling was used for maximum variation of views and experiences regarding adherence to asthma management, until the point when no new, significant data emerged from data analysis – the point of theoretical saturation was reached [32]. Forty invitations were made and five patients refused to participate, due to lack of time. Participants' names are fictional in order to preserve their anonymity.

Our methodological option was a semi-structured ethnographic interview guide, conceptualized to elicit illness narratives and status of health knowledge - the McGill Illness Narrative Interview (MINI) [33], previously applied and validated in a Portuguese study about health knowledge of people with asthma and breast cancer. MINI was chosen for being flexible, with high range of uses and had already been applied

and validated by a wide range of worldwide multidisciplinary studies such as, stress among women with scleroderma [34], myocardial infarction [35,36] or even to study illness experiences in a very specific setting as the Tibetan region of Mustang [37]. Aiming at the validation of this interview schedule in the Portuguese context, a preliminary set of pilot interviews with a purposive sample of patients with breast cancer and asthma [38]. MINI is a semi-structured ethnographic interview guide, originally comprising five sections: 1. Initial exploratory narrative; 2. Illness prototypes; 3. Explanatory models; 4. Help seeking and service utilization; and 5. Impact of illness. For the purposes of this study, it was used the validated version for the Portuguese population, comprising an additional section about health information behaviors: *After diagnosis did you ever search for information about asthma? Did someone ever search for you? What can be made to improve communication between health professionals and patients? What type of information do you consider important to be communicated in the diagnosis' consultation? What makes information trustworthy for you? Do you usually use internet to search for health information? If yes, how do you usually choose the websites?* Interviews lasted an average of 50 minutes and were conducted by the first author. All were taped, professionally transcribed verbatim, and checked for accuracy.

Data were thematically analyzed [39], as case-based and process-tracing-oriented, by the first author, with assistance of NVivo 10 (QSR International, USA, 2013) A 'line-by-line' coding of the text [40, 41] was systematically done for each interview by two researchers. Data were systematically coded and synthesized by themes, and then, categories were defined. Themes were discussed by three authors, and doubts and assistance of NVivo 10 (QSR International, USA, 2013) A 'line-by-line' coding of the text [40, 41] was systematically done for each interview by two researchers. Data were systematically coded and synthesized by themes, and then, categories were defined. Themes were discussed by three authors, and doubts and divergences were discussed until a consensus was achieved. Authors were more interested in discussing themes emergent from patients' illness narratives to better understand asthma self-management, health networks and health information seeking behavior. The first author carried out the fieldwork and initial analysis.

The thirty-five patients interviewed consisted of 21 women (7 elementary educational level, 8 secondary educational level and 6 high educational level) and 14 men (4 elementary educational level, 5 secondary educational level, 5 high educational level). Their ages ranged from 18 to 84 years old.

All participants formalized their collaboration through a written informed consent, reinforcing that patients could refuse to participate in our study at any time without any prejudice in their access to medical care services. Ethical approval was granted by the Research Ethics Committee of the Hospital de São João.

3. Results

While investigating pathways of health information behaviors in the context of their management of asthma, we learned about family involvement and influence in health information seeking behaviors in some detail. Participants' situations were diverse and several sources emerged (Figure 1): We identified two themes reflecting influence of family in asthma management. First we identified the (a) *Profiles of health information: contexts and behaviors* – describing socioeconomic characteristics, family and professionals contexts, and attitudes towards diagnosis, taking into consideration perceived quality of life and how asthma is managed; and second, we described the (b) *Sources of health information and pathways*, according to the profiles identified, describing sources and paths of health information and the level of influence and importance of each.

Theme 1. Profiles of health information: contextualizing illness experiences

We identified in 35 qualitative semi-structured interviews, two main profiles for information seeking: 1) Group 1 - Asthma is a 'family issue' (n=23/35) - 61% >35 years old, and 43% have elementary education (Table 1). Easy acceptance of diagnosis, is based upon the feeling of knowing well the condition, based on family contexts where asthma is a common condition. The prevalent attitudes towards health information was a non-seeking behavior for health information, and the group was named *non-seekers*. 2) *Group 2* - Asthma is not a 'family issue' (n=12/35), except for one participant named Sebastião – 91% have >34 years old, and 66% have higher education (Table 1). They have a prevalent health information seeking behavior and group was named the *seekers*.

Non-seekers identified causes of asthma based on hereditary causes. Participants described that it is 'something that runs in the family' to illustrate genetic explanation and emphasize asthma as a "family issue". Therefore, diagnosis was not a surprise, since it was common to find patients whose father, mother, or other family member(s) suffer or had suffered from respiratory diseases:

> *When the doctor told me "you have asthma" I already knew it. I mean, it wasn't a big surprise for me, because I come from a family of asthmatics. I suppose my grandfather died from it, my father also got it, my aunt (...) It was a matter of time until I get it.* (Samuel, M, 28y.o.)
>
> *I can pretty much trace a family path in it: my father, two of my uncles, some cousins. So, everyone deals with it normally.* (Henrique, M, 35y.o.)

Some attributed the onset of asthma to an infectious or contagion mode. Raising the question of the responsibility of asthma knowledge within a family, reflecting lack of knowledge about causes of asthma:

> *LA: How do you think that other people react to an asthmatic?*
>
> *Rosa: [silence] I don't know if…there are people…in the case of my father, he used to spit blood when coughing and all that and we advised my daughter to stay away…to prevent something bad, right? I don't know if it sticks to you [infectious] or not…*
>
> *LA: Do you think that asthma may be contagious?*
>
> *R.: In some…in certain cases, yes, I believe it is.* (Rosa, F, 39y.o.)

On the other hand, *seekers*, pointed causes of asthma to environmental factors, those more polluted, two participants had to quit their jobs – one in construction and the other in a ceramics factory; and five participants had early retirements because of asthma. This continuous exposure to hazardous settings, associated to their professions, caused respiratory problems as asthma:

> *My work caused it. There were so many hours inhaling dust, I always worked with a lot of dust, cotton, cloths…* (Sónia, F, 56y.o.)
>
> *I think it's from the environment, the pollution...where I used to live there was many factories, people used go to the hospital.* (Bárbara, F, 25y.o.)

Asthma were firstly denied by *seekers*. They were reluctant in using the medication for several reported reasons, but mainly because of the fear of its addiction side-effects. Participants described other set of limitations in their lives as a result of asthma, mostly involving constraints in professional activity, household composition, work, schooling, social life and, along with the fear of addiction to medication, and financial restrictions to buy medications, are also a barrier to use preventive medication:

> *The doctor told me to use the medication every day, even without symptoms, but each box is so expensive… I just can't buy every month. I have other problems [diseases]to buy other medications. So, I only use it when I feel sick.* (Ana, F, 52y.o.)

For some, physical activity was compromised because of the constant feeling of exhaustion, leading to isolation and withdrawal. There was a significant variability on how these restrictions affected the participants' lives, ranging from feelings of anger, incapacity, depression and frustration as the most commonly described.

Many people look and don't understand. It's horrible when you need to catch your breath, just to eat or prepare yourself to go out, because you are so tired. I feel very sad; I have been feeling very bad. I'm taking anti depressives and all that, because I feel so useless. I feel tired all the time. I even say to my husband that I am not doing anything here. I am useless because I cannot work, and there is nothing I can do. (Judite, F, 56y.o.)

As far as participants' perspectives of chronicity of asthma goes, Francisco (*seeker*) only searched for information about asthma 3 years after the diagnosis, when he finally accepted his condition of asthmatic. Francisco begin denying the asthmatic condition: *"It took me three to four years to become aware and accept the disease…I couldn't understand why."* (Francisco, 59y.o.). The awareness of having to deal with a chronic disease, in some cases, functioned as an alert and, consequently, led to a seeking behavior:

"*When I was about twelve, thirteen years old, I started looking for some information about asthma. Because I realized then that if it hadn't disappeared until that age, it would stay with me for the rest of my life. And by then, it also got worse. I had to be more careful at home and it was all quite restrictive. That's when I went looking for more information, for solutions."* (Carlota, 29y.o.).

Part of our sample were diagnosed in childhood (n=12/35), and from this group, only 6% (n=2/35) have actively searched for health information on asthma in adulthood. On opposite side, in adulthood a late diagnosis of asthma was often referred. Some participants felt relief when they were finally diagnosed, giving them the necessary medication to control asthma:

"*Every month I had pulmonary infections. But I didn't know what it was. I thought it was the flu, or colds. It took me three years to have an appointment with a lung specialist, who finally told me I had asthma* (Sebastião, M, 34y.o.).

The medication is everything. Since I've been taking it the problem started to be solved, it's our only thing, our lifeline. You take it and after a while you're fine again. (Samuel, M, 28y.o.)

Non-seekers, were generally aware of their condition and additional intricacies have emerged from different experiences and perspectives. Comorbidity was another barrier for asthma management, with seven participants diagnosed with co-occurring diseases with a major impact in their lives, like Amelia (F, 40y.o.): "*I also suffer from psoriasis, chronic urticarial, rhinitis and asthma (…) asthma is just other in the bag* ", and because of these others conditions, asthma becomes a minor concurrent problem.

Theme 2. Sources of information: attitudes and pathways

All individuals used formal sources of information, specifically the doctor (n=35/35), followed by informal sources such as family (n=24/35). Media was also pointed as a frequent source of information: television (n=12/35) and internet (n=11/35) (Figure 1).

The doctor

Information provided by the doctor was regarded as essential by all participants (35/35) as Francisco (59y.o.) says: "*the source of information here, for me, is the doctor. The doctor is the key to the information*". The doctor provides medical explanation of the symptoms, prescribes medication and offers advice on how to control crises in everyday life:

> "*After [the diagnosis] I started to adjust myself to the disease, and try to put my misery away. I thought «That's it. I will do my treatment, and I will start to feel better». My doctor explained to me everything and now I can really sense the one crisis coming, I feel it right away. And I'm never wrong*." (Judite, 56y.o.)

Regardless of trusting the information provided by the doctor, *seekers* were more pragmatic, and tried to know and learn more about asthma; therefore, they actively sought more information, combining formal and informal sources.

Family and friends

Support by family and friends were mentioned by *non-seekers* (n=24/35), as essential for integrating asthma into one's life successfully. Examples of strategies bypass some of the restrictions imposed by the condition were given in the context of physical activities and social situations.

> *I like sports and when I play football, when things get worse I stop and pull my arms above the head and take a deep breath. After a while I'm fine again.* (Isaac, M, 18y.o.)
>
> *When I am at a bar or something and I feel it a little breathless. And I came outside and use the inhaler. If I am with close friends I ask them to come with me outside, otherwise I go to the bathroom and do it.* (Pedro, M, 21y.o.)

Descriptions of how they deal with asthma draws a picture on the experiential knowledge held by participants. The influence of relatives who have had asthma provided examples about how to best handle asthma symptoms, including homemade vaporizations and infusions; most strategies were learned from

relatives before diagnosis of asthma. These prototypes and shared knowledge helped patients feel more accommodated with the condition – whose mother, father or other family member(s) suffered or had suffered from asthma (n= 23/35):

> *My father also had it, just like his whole side of the family. And he used to give me some of his medications when I was feeling bad, you know. And that helped.* (Henrique, M, 35y.o.)
>
> *"Well, since I remember, my father had always lungs problems. Lots of difficulties to breathe. My father smoked a lot. And he died due to smoke. I always saw my father with those coughs, always, always, always… until he just couldn't breathe anymore and faint. My father was like that.* (Amélia, F, 40y.o.)

The Internet and television

Contrarily to *non-seekers*, *seekers* actively searched for information about asthma, for multiple reasons. Firstly, given their lack of familiarity with asthma, they aimed to: 1. improve their knowledge of how to control symptoms, 2. become aware of risk factors and 3. clarify medical treatments and medication prescribed by the doctor. Regarding pathways of information seeking, the first choice for source of additional information was the Internet (Figure 1), a fact illustrated by this group as the logical pathway:

> "*It was a mixture of information that I picked up on the Internet… I search on the Internet because I want to know more about the disease. It's there, it's easy.*" (Beatriz, 30y.o.)

The Internet has rapidly expanded to address the demand for medical information on health-related topics. Indeed, health topics were widely prevalent and often sought on the Internet by both consumers and providers of health information.

> "*Yes, I've looked several times in the Internet (…). Once, I've seen a situation of someone who was in a vegetative coma for not having the pump with him during an asthma attack. (…) Also, it's funny, once my dad cut out a piece of the newspaper, with a story of an asthmatic, and gave me to see.*" (Alice, 34y.o.)

In what concerns Internet, difficulties to deal with the complex amount of health information was one of the major issues highlighted by participants. For instance, Sebastião (M, 34y.o.), regular internet user, said he felt overwhelmed with all the information he found on the Internet and didn't learned too much about asthma: "…*I didn't learn too much, the quantity of information is so overwhelming that I never know if I learn more or if I get more confused*…". Sebastião, was the only *seeker* with asthma in the family, that

searched for health information about asthma regularly, for two reasons: (a) he was convinced doctors didn't have time in medical consultations to clarify many things and (b) he witnessed his mother struggling all life with a severe asthmatic condition:

> *"I was [when diagnosed with asthma] so sad, angry, everything. It was really hard for me to deal with it. I was aware that it was going to get worse; I had the notion that I could die of it… I see my mother [also asthmatic] What she suffers. What she has been suffering all these years (…) So yes, I felt the need to know more. And, truth is that at the medical appointments I usually don't have time to ask more. So, I already searched on the Internet*." (Sebastião, M, 34y.o.)

4. Discussion and Conclusion

This study provides insights into how people diagnosed with severe asthma, manage the disease in their everyday lives, and highlights the important role of informal social support in the management of asthma. This study identified, firstly, the *seekers*: (i) without family history of asthma (except one); (ii) ranging from low to appropriate health literacy; (iii) firstly deniers of the condition of asthmatic but later accepting it and becoming more pragmatic. And secondly, the *non-seekers:* (i) with family history of asthma; (ii) also ranging from low to appropriate health literacy; (iii) and good acceptance of the condition based on family 'prototypes'. However, we didn't find *non-seekers* without family history of asthma. This missing group is probably common in different medical settings, particular in basic care centers, where theoretically we could find asthmatics, with a less severe condition - intermittent or mild persistent asthma.

Due to family prototypes, asthma as 'family issue' appeared as the major determinant of health information seeking behavior, determining the borderline between accepting and denying the asthmatic identity. A growing body of evidence suggests that patient and family engagement can lead to better health outcomes [42], contribute to improve quality of life of patient [43] and help control health costs [44]. Our findings suggest that sharing decision-making is made within family contexts and calls attention to the importance of studying the distributed health literacy [45] of each individual in order to better understand the shift of responsibilities of patients and families in health care. Previous studies focused specifically on social identities of being asthmatic already used these categories of deniers and accepters and how these two different attitudes will affect compliance with medication [46]. Other studies discussed health information seeking behaviors and how the type of information sought depend on the stage and type of illness, classifying consumers in three groups: seekers, weavers and avoiders [46], and how information orientation

according to those different groups can facilitate the development of targeted health information approaches [47]. As our study also discusses, this differentiation of groups provides insights of health information behaviors and health information engagement crucial to the design of tailored health communication strategies.

In terms of asthma management, our findings show that the intake of preventive medication appears as a major problem due to financial restrictions, and later to the fear of becoming dependent of the medication, leading to online search for natural solutions. If it is a fact that online health communication offers opportunities for customization which were unimaginable a few decades ago, there's still a long way to go to achieve the potential of health communication [48-52]. The influence of family in health information seeking behavior plays huge influence, but only if asthma is a shared condition among close family members.

Chronic illness as a family issue often implies that knowledge is otherwise shared and diffused, and that Internet as an information source has not the same meaning, or is differently used by those sufferers. And, although this kind of knowledge shared in the family is helpful to the management of asthma and to the acceptance of the identity of asthmatic, sometimes it leads to some passivity and ways to improve patient's condition might be ignored [9,53,54]. This partnership between patient and their families should be optimized with the help of health professionals, in order to provide a patient-centered care, quite relevant to better therapeutic relationship [55]. Patients with no asthma in the family need more support after diagnosis, in order to reduce the stress caused by diagnosis and help to the compliance with treatment as soon as possible.

The key strength of this research suggests that engagement of patient and family in the management of asthma, can be a way toward achieving better management, enhanced quality of care, and greater cost proficiency. This imply a more deliberate or pro-active policy to involve patients' family in treatment programs, in clinical procedures and patient management plans. This wider perspective could inspire health professional if family is seen as 'shared knowledge and capability'. Evidence support that family engagement in information practices appeared quite significant - patients with asthma in the family have asthma better controlled, when comparing with the group of seekers, but future research would be needed for deeper understanding.

Limitations of the Study

This study has several limitations to consider. More women than men agreed to be interviewed, thus limiting the possibility of gaining insight into possible gender differences in the experience of health information seeking behavior or self-management of asthma. Recall bias was inevitable as patients recalled experiences extending as far back as to childhood. We did not interview family members about their own perspective on family care. The findings are limited by the sample size, and the cross-sectional nature of the study design, not being able to predict possible behavior changes through time. Given the particular context of our setting, with patients suffering from mild to severe asthma, we might have missed other sources of information that did not emerge in the interviews, and that can explain why we don't have nonseekers without asthma in family history.

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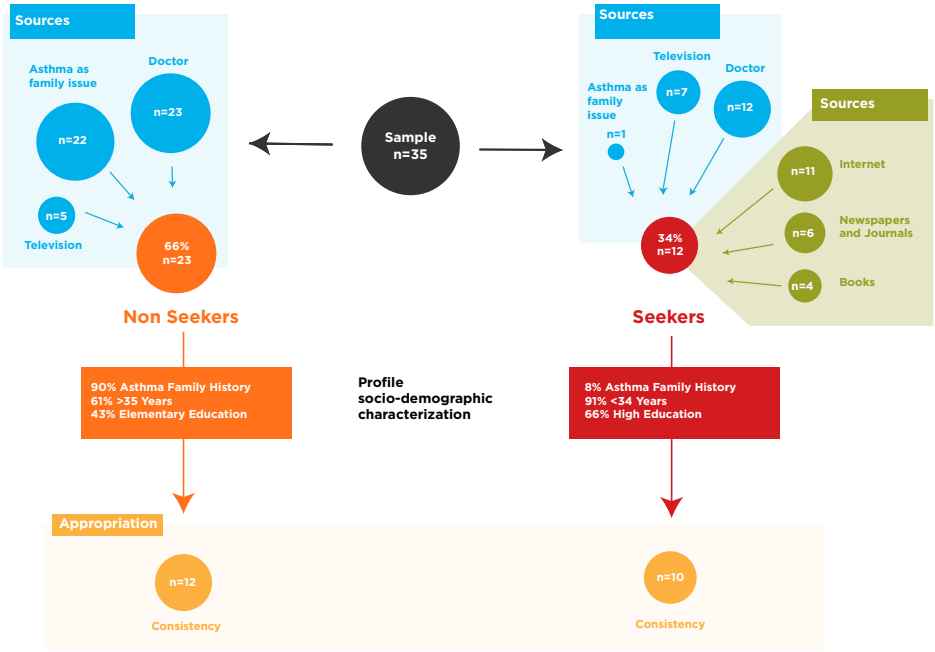
Table 1. Participants characteristics

Interview	Name (alias)	Gender	Age	Educational level	Asthma in the close family
Non-seekers					
P1	Carla	F	31	Secondary	Yes
P2	Samuel	M	28	Secondary	Yes
P3	Isabel	F	56	Elementary	Yes
P4	Filipe	M	32	Elementary	Yes
P5	Judite	F	56	Elementary	Yes
P6	Rosa	F	39	Secondary	Yes
P7	Miguel	M	84	Elementary	Yes
P8	Ana	F	52	Secondary	Yes
P9	José	M	43	Secondary	Yes
P10	Marisa	F	59	Elementary	Yes
P11	Joel	M	21	High	Yes
P12	Amelia	F	40	Elementary	Yes
P13	Guilherme	M	18	Secondary	Yes
P14	Henrique	M	35	Secondary	Yes
P15	Cristina	F	42	Secondary	Yes
P16	Elsa	F	25	Secondary	Yes
P17	Leonardo	M	74	Elementary	Yes
P18	Raquel	F	75	Elementary	Yes
P19	Milena	F	46	Elementary	Yes
P20	Hugo	M	74	Elementary	Yes
P21	Maria	F	25	Secondary	Yes
P22	Benjamin	M	28	High	Yes
Seekers					
P7	Francisco	M	59	High	No
P10	Sofia	F	29	High	No
P16	Sebastião	M	34	Secondary	Yes
P18	Marlene	F	21	High	No
P19	Carolina	F	34	High	No
P20	Leonor	F	32	Elementary	No
P21	Beatriz	F	30	High	No
P29	Camila		18	Secondary	No
P30	Filipa	F	20	High	No
P31	Simone	F	41	Secondary	No
P32	Barbara	F	25	High	No
P33	Pedro	M	21	Secondary	No
P34	Isaac	M	18	High	No

Figure 1. Distribution of sources of information



4.4 Paper IV. Patient-centered communication in type 2 diabetes: facilitating and constraining factors in clinical encounters

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(Under review)

Patient-centered communication in type 2 diabetes: facilitating and constraining factors in clinical encounters

Abstract

Objective

To explore the perceptions on the constraining and facilitating factors to patient-centered communication in clinical encounters of patients with type 2 diabetes and the providers involved in their care.

Data sources/Study setting

Patients and providers involved in diabetes care in Northern Portugal.

Study design

Seven focus groups with 12 providers and 33 patients.

Data collection/extraction methods

Analysis was based on grounded theory using open, axial and selective coding.

Principal findings

Patients focused on the patient-provider relationship, while providers emphasized constraining factors when exchanging information and facilitating factors regarding disease and treatment-related behavior. Patients and providers both agreed on some constraints (power imbalance, patients' avoidance reprehension and disease negligence, use of jargon, and insufficient competencies and consistency between providers) and facilitators (seeing patients-as-persons, providing tailored information in plain language, and recognizing the 'wake up call'). Patients perceived an aggressive attitude as a barrier to communication but providers perceived it as a facilitator. Patients included issues related with trust, respect, and psychosocial support as important factors to them. Only providers mentioned the influence of macro-level interventions and patients' socioeconomic position as essential factors.

Conclusions

Improvements on patient-centered communication depend on fostering the patient-provider relationship, patients' participation and involvement, and training providers' communication skills.

Keywords: Diabetes mellitus, type 2; patient-centered; communication; patients; health personnel, physician-patient relations

Introduction

Approximately 422 million adults worldwide were estimated to have diabetes in 2014, and this number is expected to rise to 700 million people by 2025 (NCD Risk Factor Collaboration - NCD-RisC 2016). This projection is due primarily to the growing prevalence of type 2 diabetes, closely following population aging, overweight, obesity, and unhealthy lifestyles (NCD Risk Factor Collaboration - NCD-RisC 2016). Over 1.5 million people die of diabetes each year, and diabetes ranks 6th as a cause of death globally (World Health Organization 2016). It also represents one of the leading causes of disability, resulting from associated complications, including acute myocardial infarction, stroke, blindness, renal failure, and lower limb amputations (GBD 2016 Disease and Injury Incidence and Prevalence Collaborators 2017). In 2015, Portugal was estimated to have the highest age-adjusted prevalence in adults aged 20-79 years of the European Union; its crude prevalence was estimated at 13.6% (International Diabetes Federation 2015). Aiming to reduce the morbidity and mortality burden, both the Chronic Care Model and the World Health Organization's Innovative Care for Chronic Conditions emphasize the need for patient-centered care and self-management support for people with chronic illnesses (Bodenheimer, Wagner, and Grumbach 2002; Noncommunicable Disease and Mental Health Cluster: World Health Organization 2002).

Patient-centered communication is acknowledged as a core dimension of patient-centered care (Institute of Medicine Committee on Quality of Health Care in America 2001; International Alliance of Patients' Organizations (IAPO) 2007). Moreover, communication is considered a basic clinical competency and communication skills have been regarded as a crucial component of the health literacy of providers (Coleman et al. 2009; Rudd 2010). In the context of type 2 diabetes, patient-centered communication has been associated with improved disease knowledge (Skinner et al. 2008), self-care (Brenk-Franz et al. 2017), quality of life (Williams et al. 2016) and better measures of metabolic control (Hojat et al. 2011; Parchman, Zeber, and Palmer 2010; Parker et al. 2017). In line with this evidence, leading organizations including the American Diabetic Association and the International Diabetes Federation, currently advocate for this type of communication in the management of diabetes (American Diabetes Association 2018; International Diabetes Federation 2012). Furthermore, patients and patient advocacy organizations have expressed a desire for more personalized and humane medical care (Bensing, Rimondini, and Visser 2013; International Alliance of Patients' Organizations (IAPO) 2007). In spite of these recommendations, results from the DAWN2 (Diabetes Attitudes, Wishes and Needs) study suggest that patient-centered care is often unavailable and that the psychosocial needs of

patients with diabetes worldwide are not being met (Nicolucci et al. 2013), at least partly due to communication failures between providers and patients with diabetes (Beeney, Bakry, and Dunn 1996; Freeman and Loewe 2000; Linetzky et al. 2017). Communication failures are one of the most common patient complaints and contribute to patient harm (Crico Strategies 2015; Reader, Gillespie, and Roberts 2014). This is especially problematic in people with lower health literacy, with whom health professionals report feeling unprepared to communicate with (Ali et al. 2014). Consequently, several experts have proposed clear communication and health literacy curricula for health professionals in the United States (Coleman, Hudson, and Pederson 2017; Coleman and Fromer 2015) and Europe (Karuranga et al. 2017). Training in these competencies has shown potential to improve communication skills in the short term (Coleman and Fromer 2015; Kaper et al. 2018; Pagels et al. 2015; Sullivan et al. 2011), but it has been suggested that training would have to be ongoing, as improvements were not sustained (Coleman, Peterson-Perry, and Bumsted 2016).

Patient-centered communication between patients with diabetes and the providers caring for them is paramount to fill the gap between recommendations and clinical practice (Bensing et al. 2013; Ishikawa, Hashimoto, and Kiuchi 2013). Reconciliation between perspectives from various stakeholders has been pinpointed as essential to improve clinical communication. Therefore it is important to involve both patients and providers in the dialogue about effective patient-centered communication in order to develop new, or improve upon existing, people-centered health services (World Health Organization 2015). Literature from communication theories provides recommendations for effective patient-centered communication at the following dimensions: fostering healing relationships, making decisions, exchanging/gathering and providing information, responding to emotions, and enabling patient self-management/disease and treatment-related behavior (de Haes and Bensing 2009; Epstein and Street Jr 2007; King and Hoppe 2013). However, the few studies that addressed the constraining and facilitating factors to patient-centered communication with patients with type 2 diabetes have mostly disregarded communication theories in framing these issues (Abdulhadi et al. 2007; Mulder et al. 2015; Ritholz et al. 2014).

We aimed to explore the perceptions on the constraining and facilitating factors to patient-centered communication in clinical encounters of patients with type 2 diabetes and the providers involved in their care, highlighting matches and mismatches to potentiate areas for improvement from both sides.

Materials and Methods

A qualitative study involving focus groups was conducted including patients with diabetes and providers caring for people with type 2 diabetes, in Northern Portugal. Participants were purposively sampled to include the standard range of areas of expertise involved in the care of type 2 diabetes patients in Portugal (family medicine, endocrinology, nursing, pharmacy, nutrition, ophthalmology, nephrology, vascular surgery, psychology), and the typical range of diabetes micro- and macrovascular complications (without any, diabetic retinopathy, diabetic nephropathy, diabetic foot, ischemic heart disease and cerebrovascular disease). The number of focus groups was pre-determined based on these characteristics, aiming for maximum variation of provider roles and patient's disease burden (assuming that those with more serious complications tend to have higher disease burden). This number was not surpassed because data saturation was reached. Within groups heterogeneity was pursued regarding age and professional experience/disease duration. An individual direct approach was used to recruit providers working on primary care and hospital care from several health institutions other than the ones from where patients were recruited. Individual physicians working in one primary care health center and five different hospital departments (Ophthalmology, Nephrology, Diabetic Foot, Cardiology and Neurology) from one university hospital were contacted and asked to directly invite patients without complications and with specific complications, respectively. We conducted two focus groups of providers in 2012 in a research institute and five focus groups of patients between 2015 and 2016 in a health center for the group without diabetes complications and a hospital for the remaining groups. Participant characteristics can be observed in table 1.

All focus groups followed the same semi-structured set of questions aimed at capturing the experiences in communication between patients living with type 2 diabetes and their providers. Questions were developed by the authors based on literature linking patient-centered communication and health literacy communication strategies. They covered factors that constrain and facilitate communication, patients' information needs, and methods used for gathering and providing information. All the focus groups included a trained moderator and a co-moderator. Focus group discussions lasted from 56 to 93 minutes, with a median duration of 90 minutes. The audio of the focus groups was recorded, professionally transcribed verbatim and checked for accuracy.

Data were analyzed independently by the first two authors according to the grounded theory (Bryant and Charmaz 2007), using NVivo 10 (QSR International, USA, 2013), and merged by consensus

following continuous and iterative discussions, to strengthen coding consistency. This triangulation was further supported by the researchers' different backgrounds (medicine and sociology). In addition, classifications were always discussed and validated by the last author. Open coding, axial coding and selective coding were used. Quotations with similar meanings were synthesized into categories (open coding), which were then put together into themes (axial coding), and then into core themes (selective coding). During selective coding, inductive themes were laden with interpersonal patient-centered communication theory in consultation with existing literature (de Haes and Bensing 2009; Epstein and Street Jr 2007; King and Hoppe 2013). The most illustrative verbatim quotes were selected by the first and the second authors, and the translation checked by an English native speaker.

The Ethics Committees of Instituto de Saúde Pública da Universidade do Porto, Centro Hospitalar de São João, and Centro Hospitalar do Porto granted ethics approval for the study, and the National Centre for Data Protection approved data collection. All participants formalized their collaboration through written informed consent.

Results

Table 2 summarizes the constraining and facilitating factors experienced by participants during communication in clinical encounters, grouped by patients and providers, in relation with the three core themes that emerged from data analysis: 1) 'patient-provider relationship', which included the leading values, roles and responsibilities of patients and providers when dealing with psychosocial distress and emotions, and partnership in decision making; 2) 'disease and treatment-related behavior', when quotations pointed out issues emerging from communication to enable self-management, behavior change or maintenance; and 3) 'gathering and providing information' where the factors included references to information exchange, as well as to the methods used to respond to information needs. The constraining and facilitating factors are illustrated by anonymized quotes drawn from the focus group interviews presented in the text and supplemented by Tables 3 and 4, respectively.

Constraining factors (Table 3)

The patients and providers interviewed for this study agreed that power imbalance (C1a; C1b), avoidance of reprehension by patients (C1c; C1d), patients' neglect of the disease (C2a; C2b), use of jargon (C3a; C3b), inconsistency between providers (C3c; C3d) and insufficient competencies of

providers (C3e; C3f) were constraining factors to effective patient-centered communication in clinical encounters. The misrecognition of power imbalance as natural, necessary, and legitimate refrained patients from asking questions and supported non-disclosure of medical information, particularly about high self-monitored glycemic values, because they didn't want to be reprimanded. Providers acknowledged that patients lied to them, but they did not attempt to change it:

> *We think we are being lied to, but we also don't tell them [the patients]: 'I don't understand what you are telling me', right?* (FG7).

Inconsistency between different providers was especially challenging for patients, who stated sometimes being harmed by conflicting or inaccurate recommendations:

> *I lost nine and a half kilos in a month and a half because here [at the hospital] someone incorrectly informed me of the type of diet I should be doing, right? And I almost died of starvation.* (FG5)

Only patients mentioned non-supportive (C1e) and/or distrustful (C1f) patient-provider relationships, inadequate response to emotions (C1g), disrespect for basic courtesy behaviors (C1h), an aggressive attitude from providers to motivate adherence to recommendations (C2c), and the use of inappropriate analogies, such as describing a banana as an expensive potato instead of providing nutritional recommendations for diabetes (C3g), as constraining factors. Patients described episodes when doctors gathered around them, discussing them as cases while ignoring their presence, and when they did not address their concerns:

> *Sometimes they leave the offices ranting because the doctor didn't address their concerns.* (FG2).

They also argued they did not have help from providers to build meaning around why they had diabetes (C1i), and named situations of ineffective communication when providers were blunt, hurting their feelings and walking away, leaving them without psychosocial support, as well as when they felt disrespected as patients and human beings:

> *This year in May I had another appointment with her. (...) I got there and I waited for two and a half hours. I left, as I had to get to work. (...) Then my doctor wrote another letter and I went there again. And then she said: 'Did you bring any tests?' 'No, I didn't. I haven't been here in two years, what tests would you like me to bring?' 'If you came for prescriptions, it's no use, you're not getting any.' And I said: 'Look, I actually have someone I can ask for prescriptions' and I walked out the door... and she didn't assist me and I walked out the door and left.* (FG3)

Providers seemed to partially dismiss their own responsibility in communication improvement towards behavior change by suggesting it was the role of other professionals (C2d). They added constraints related with the patients' family obstruction (C2e) and their low health literacy (C2f) and socioeconomic position – education (C2g) and income (C2h) that caused lack of access and understanding of health information to better manage the disease:

> *I have patients that see me and at first sight: Please read this to me because I don't know how to read. I don't know how to take these medicines. (FG6).*

The lack of time to communicate effectively (C3h) and the low patients' literacy and education (C3i) sometimes were used as justifications for not routinely checking for patient's understanding (C3j) and for being unaware of patients' information needs (C3k).

Facilitating factors (Table 4)

Seeing patients as persons (F1a; F1b), providing tailored health information in plain language (F3a; F3b), and recognizing the 'wake-up call' (a critical moment typically caused by a scare such as a complication of the disease or the near death of someone close) as an opportunity to improve communication between providers and patients (F2a; F2b), were regarded by both groups as facilitators to effective communication. Patients focused on the need for practical management information, i.e., knowing exactly how certain behaviors should be performed (F2c) and what to do in specific situations such as switching doctors (F2d), and expressed the desire to participate in peer group meetings for that purpose (F2e). Providers highlighted the importance of adjusting the information to the patients' day-to-day context (F2f) and comorbidities (F2g). Some patients stated that playing a more active role in consultations by looking providers in the eye and asking direct questions helped them facilitate communication (F1c), while providers claimed for more shared decision making (F1d) through increased collaborative goal setting:

> *I always hope to be able to somehow negotiate with the individual what his plan is. Negotiate that is to say, make this something two-sided that is not prescriptive.* (FG6)

Only patients mentioned the use of analogies as an important tool to facilitate communication (F3c), and suggested additional factors mainly related with the patient-provider relationship, such as being actively listened to and building a trustworthy relationship (F1e), and receiving psychosocial support from providers who recognized their distress and helped them recover (F1f), sometimes using humor:

We [patient and nurses] all played, talked, in a friendly, spontaneous way (...) laughed, told jokes... [as a way to relieve distress] (FG5)

Providers, on the other hand, focused on overcoming barriers related with communication of recommendations to promote behavior change, namely: increasing patients' responsibility by holding them accountable and providing knowledge (F2h); using an aggressive communication style (F2i) or a positive one by reinforcing the benefits of adherence to recommendations (F2j); investing in diabetes educators (F2k); receiving support from the family to facilitate the engagement on healthier choices, in particular those related with eating habits (F2l); and macro-level interventions, such as overtaxing unhealthy foods (F2m), investing in children's health literacy in schools (F2n), or even building more trails for people to exercise more (F2o). Providers also defended increasing consistency of information provided to patients (F3d) and improving their communication skills through training (F3e) as facilitating factors related with gathering and providing information. Having more time to communicate with the patient also emerged as a facilitator to communication in clinical encounters (F3f), creating the opportunity to repeat information to improve understanding (F3g).

Discussion

This study identifies several aspects that can be useful in improving patient-centered communication in type 2 diabetes both from the side of patients and providers. They may help in fostering the patient-provider relationship, patients' participation and involvement, and providers' communication and relational skills, in a context where the perceptions of the patients and the providers may apply to other chronic diseases.

Our data suggests a mismatch between what is more valued by patients and providers in clinical communication. The finding that patients tended to be more focused on interactional factors (e.g., trust, respect, use of analogies, and supportive patient-provider relationships) and providers on system-level factors (e.g. availability of diabetes educators, patient and family socioeconomic position, macro-level interventions, and lack of time) whereas each of these factors almost did not come up for the providers and patients, respectively, draws attention to the need to promote participatory care planning and delivery through active dialogue between representatives of decision-makers, providers, patients and caregivers, where knowledge and experiences can be elicited and exchanged and transformative change, i.e. change leading to more equitable and dialogic relationships, can emerge. As part of what

has been called relationship-centered care, treating patients with consideration and respect and providing psychosocial support is essential in establishing and maintaining trust (Beach, Inui, and the Relationship-Centered Care Research 2006). Although promoting trust is at the core of medical communication curricula (General Medical Council 2013; Mirza 2010) and patient centered-communication (Hall et al. 2001; International Alliance of Patients' Organizations (IAPO) 2007), this study calls attention to the need of constant sensitivity in enacting such guidelines throughout daily clinical encounters. Narrative medicine, or 'the clinical practice fortified by narrative competence—the capacity to recognize, absorb, metabolize, interpret, and be moved by stories of illness', might help to improve attentive, empathic, and person-centered care and communication (Arntfield et al. 2013; Charon 2001). Lack of time is a common justification not to provide person-centered care (Mulder et al. 2015; Peyrot et al. 2005), but in contrast with earlier findings, patients did not mention short consultations as a barrier (Rocque and Leanza 2015). This may reflect their resigned acceptance of a social norm that is perceived as immutable or the fact that they place higher value on overcoming health literacy related barriers and on fostering the relationship dimension in communication.

Our data suggest that patients regarded an aggressive attitude as a barrier, while some providers viewed it as a facilitator to persuade patients to change their behavior. The latter perception is also in conflict with chronic disease management guidelines and communication curricula that encourage supportive communication styles to promote behavior change (American Diabetes Association 2018; General Medical Council 2013; International Diabetes Federation 2012). These recommendations support the need of motivational interviewing by providers, using an empathic non-confrontational style to increase motivation for behavior change, engage patients with treatment and build therapeutic relationships (Chen et al. 2012; Christie and Channon 2014; Dellasega et al. 2010; Hardcastle, Blake, and Hagger 2012; Wens et al. 2005). Nonetheless, there is still no consensus on the outcomes of threatening interpersonal communication, with recent literature showing contradictory results (Kok et al. 2018; Ruiter et al. 2014; Tannenbaum et al. 2015). Future studies should explore the effect of communicator styles on patient-oriented outcomes.

The patients and the providers interviewed for this study agreed on some constraining factors related with gathering and providing information (use of jargon and insufficient competencies and consistency between providers), patient-provider relationship (power imbalance and avoidance of reprehension by patients) and disease and treatment-related behavior (patients' neglect of the disease), pointing to

common strategies to facilitate effective patient-centered communication in clinical encounters - using plain language, seeing patients as active persons, providing tailored practical information, and recognizing the 'wake-up call' as useful and a 'teachable moment' (Lawson and Flocke 2009), i.e., a crucial moment to prompt investment in communication towards lifestyle and treatment-related change. The use of technical language or medical jargon is a commonly acknowledged barrier to effective communication, particularly in chronic disease management (The Joint Comission 2007), that reinforces the power imbalance in communication in clinical encounters (Bourdieu 1977). Patients' neglecting the disease may partially be explained by lack of clear-cut explanations concerning diagnosis and disease causation in a language or with analogies that they are able to understand (Wens et al. 2005). Inconsistency between different sources of health information, e.g. providers, undoubtedly decreases the likelihood of patients´ taking action or changing their behavior based on that information (World Health Organization 2017). Avoidance of reprehension behavior has also been reported in other studies (Ritholz et al. 2014) and relates to the concept of being a 'good patient', in which patients seek to present themselves to their doctors as compliant and grateful individuals (Katz 2000; McCreaddie and Wiggins 2009). It is deeply rooted in the power imbalance typical of a paternalistic model of care and aims to avoid judgment and confrontation (Katz 2000).

Lower health literacy and education, as well as an adverse socioeconomic context, can make communication more challenging Clear communication strategies are essential to address these difficulties and may help lessen health literacy demands for patients (Bailey et al. 2014; Brega AG et al. 2015; Stableford and Mettger 2007). However, receiving clearer information does not necessarily equate with behavior change, such as leading healthier lifestyles, but patients become better equipped to make decisions regarding their health (U.S. Department of Health and Human Services. Office of Disease Prevention and Health Promotion. 2010).

Strengths and limitations

The findings of this study can be used as a baseline to subsequent quantitative or qualitative studies within different populations and other chronic illnesses, contributing to relevant literature in the field of effective patient-centered communication. The inclusion of participants across the whole spectrum of type 2 diabetes complications as well as all the health professions involved in their care is also a

strength of this study. Previous studies including patients and providers focused on only one type of provider (Freeman and Loewe 2000; Karhila et al. 2003; Ritholz et al. 2014).

The possibility of selection bias from physicians recruiting patients and from the research team in recruiting providers cannot be excluded. The clinical setting where the group discussions of patients took place may have hampered full disclosure of barriers to effective communication, and in addition, group interviews may have limited discussion of factors related to Social Determinants of Health, in particular among patients who may have felt uncomfortable acknowledging these issues in a group.

We did not aim to assess differences in perceptions among providers or among patients and future studies should explore them, assessing the constraining and facilitating factors in patient-centered communication according to clinical and social characteristics. In other countries and health settings where more diverse staffing roles are available, mapping out health literacy mediators and including them in the dialogue about effective patient-centered communication could help bridge the gaps between patients and providers (Abreu et al. 2018). Although there is a time gap between the two sets of focus groups (2012 for providers vs. 2015-2016 for patients), recommendations for type 2 diabetes care did not meaningfully change in that period.

Implications for practice

Providers in general and physicians in particular, as well as patients, need to be aware of the core dimensions of patient-centered communication. Providers need more training in motivating patients to change unhealthy or unfavorable behaviors to promote and improve their health. Overcoming patient's health literacy barriers to communication is not enough for effective communication to occur. Providers should make more of an effort to foster a therapeutic relationship with their patients, by actively listening, building rapport and connection, showing empathy, and respecting patients' values and decisions. Furthermore, patients can claim a more active role in communication and health institutions should help patients better navigate their services, as well as promote and steer them toward patient discussion groups to support peer distributed health literacy to enable disease and treatment-related behavior.

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Table 1. Sample characteristics

Type of participants	Total (n=45)	Focus group 1 (n=7)	Focus group 2 (n=7)	Focus group 3 (n=5)	Focus group 4 (n=7)	Focus group 5 (n=7)	Focus group 6 (n=6)	Focus group 7 (n=6)
Patients	33	Without complications	Diabetic retinopathy	Diabetic nephropathy	Diabetic foot	Ischemic heart disease or cerebrovascular disease		
Providers	12						Primary care physician, nurse, nutritionist, pharmacist, ophthalmologist, vascular surgeon	Endocrinologist, nurse, nutritionist, pharmacist, psychologist, nephrologist
Gender, n								
Female	17	4	4	0	1	2	4	2
Age in years, n								
<50	12	1	2	0	1	1	3	4
50-65	23	2	4	2	5	5	3	2
>65	10	4	1	3	1	1	0	0
Length of professional experience/disease duration, n								
< 1 year	4	0	1	0	0	3	0	0
1-9 years	15	3	2	1	2	2	2	3
≥10 years	26	4	4	4	5	2	4	3

Table 2. Outline of the factors influencing patient-centered communication viewed by patients and providers

	Constraining factors [C]		Facilitating factors [F]	
	PATIENTS	PROVIDERS	PATIENTS	PROVIDERS
Patient-provider relationship				
Power imbalance [C] / patients playing more active role [F]/ increasing partnership in decision making [F]	✓	✓	✓	✓
Patients avoiding reprehension	✓	✓		
Non supportive [C] / patient-as-person [F]	✓		✓	✓
Mistrusting [C] / trusting the provider [F]	✓		✓	
Lack of [C] / psychosocial support [F]	✓		✓	
Disrespecting the patient	✓			
Patients not being helped to give meaning to diabetes	✓			
Disease and treatment-related behavior				
Patient neglecting disease [C] / increasing patients' responsibility [F]	✓	✓		✓
Aggressive attitude [C/F] / positive communication approach [F]	✓			✓
Dismissing providers' responsibilities [C] / investing in diabetes educators [F]		✓		✓
Family obstruction [C] / family support [F]		✓		✓
Patients' low health literacy/education/income		✓		
Providing tailored practical information			✓	✓
Wake-up call			✓	✓
Macro-level interventions				✓
Gathering and providing information				
Use of jargon [C] / plain language [F]	✓	✓	✓	✓
Consistency between providers: lack of [C] / increased [F]	✓	✓		✓
Providers' skills: low competence [C] / improving communication [F]	✓	✓		✓
Analogies: inappropriate [C] / appropriate [F]	✓		✓	
Time: lack of [C] / more time [F]		✓		✓
Not checking understanding [C] / repeating information [F]		✓		✓
Unawareness of patients' needs		✓		
Low patients' literacy/education		✓		

Table 3. Participant quotes illustrating communication factors related with the patient-provider relationship

1 Patient-provider relationship
1.1 Power imbalance (C)/ patients playing a more active role (F) / increasing partnership in decision-making (F)
[1.1a] Provider: There is an unbalanced relationship between the patient and the health professional (...) If I believe I'm right, you [patient] will do as I tell you because I was buried in textbooks studying that for many years to help you. That is a huge barrier, right? The power imbalance in that relationship. (FG7) [1.1b] Patient: Any patient talking with the doctor knows which side of the barricade he is on. (...) There are patients that do not heal faster because they sometimes have doubts and are almost humiliated asking questions. (FG4) [1.1c] Patient: I had squabbles with doctors before, it is not that they showed me disrespect but: "You don't know. Are you the doctor?" and I reply: "In fact I am not a doctor, not even close, but I am my own man, and being my own man I know my resolution to get better"... My suggestion is... to look the doctor in the eye and say: "Doctor, what is wrong with me?" (FG4) [1.1d] Provider: I always hope to be able to somehow negotiate with the individual what his plan is. Negotiate that is to say, make this something two-sided that is not prescriptive. (FG6) [1.1e] Provider: Doctor and patient, side by side, both deciding, agreeing... (FG7)
1.2 Patients avoiding reprehension (C)
[1.2a] Patient: [Asked if she had told the doctor that she had had very high blood glucose readings because she did not take her diabetes medication] Oh no! He would reprimand me [laughter]! (FG2) [1.2b] Provider: Then they even give themselves the luxury of... nowadays the devices [glucose meters], most of them have memory... but they don't take them to the doctor and [instead they] make all the values up to show the doctor because doctors nag them, because doctors chew their ears off. (FG6) [1.2c] Provider: We think we are being lied to, but we also don't tell them [the patients]: "I don't understand what you are telling me", right? (FG7)
1.3 Non-supportive (C)/patient-as-person (F)
[1.3a] Patient: In a group consultation, when they [providers] come to the hospital ward one day of the week, sometimes Tuesday, sometimes Thursday, when it suits them, three or four doctors come with the doctor in charge [...] and tell her [the doctor in charge] "This is Mrs. Mary, she was admitted for this and that." I mean... we don't hear an explanation. (FG4) [1.3b] Patient: Sometimes they [patients] leave the offices ranting because the doctor didn't address their concerns. (FG2) [1.3c] Patient: I agree with that doctor of a certain age that could be my grandfather, he listened to me like a priest in confessional, and told me: "You have to look after yourself and do more or less what you feel is right" [feeling heard]. (FG4) [1.3d] Provider: The approach to diabetes is not the approach to diabetes or the diabetic. It is the approach of a human being in front of us that will probably have information. (FG7)
1.4 Mistrusting (C) / trusting the provider (F)
[1.4a] Patient: The trust between the "patient-doctor" is fundamental because [...] a person that doesn't have trust... it's complicated. (...) In health centers it's complicated [to ask for shifting the doctors based on mistrust]. If the person doesn't trust the doctor... "Look I don't want this doctor because I don't trust him." And where is trust? I mean it is not something that comes in a box and you can show it doesn't fit. It's hard. (FG5)
1.5 Lack of (C)/ psychosocial support (F)
[1.5a] Patient: A nurse came to do my dressing, removed that skin that was the callus and the doctor says out of nowhere: "Mrs. Mary, that finger is not going to make it!" Like that and I immediately started to cry. [...] And she [doctor] walks away, for God's sake! (…) The nurse says: "Don't worry because your finger is not lost, when you came in it was much redder, it had infection but now is looking better". (FG4) [1.5b] Patient: We (patient and nurses) all played, talked, in a friendly, spontaneous way (...) laughed, told jokes... [as a way to relieve distress] (FG5)
1.6 Disrespecting the patient (C)
[1.6a] Patient: This year in May I had another appointment with her. (...) I got there and I waited for two and a half hours. I left, as I had to get to work. (...) Then my doctor wrote another letter and I went there again. And then she said: "Did you bring any tests?" "No, I didn't. I haven't been here in two years, what tests would you like me to bring?" "If you came for prescriptions, it's no use, you're not getting any." And I said: "Look, I actually have someone I can ask for prescriptions" and I walked out the door... and she didn't assist me and I walked out the door and left. (FG3) [1.6b] Patient: We had a few doctors that didn't even greet people. (FG5)
1.7 Patients not being helped to give meaning to diabetes (C)
[1.7a] Patient: [Questioned about having asked the doctor after saying that he did not know why he had diabetes] I have already asked but that she doesn't... uh... doesn't know how I picked this up too... (FG2)

Table 4. Participant quotes illustrating communication factors related with disease and treatment-related behavior

2 Disease and treatment-related behavior
2.1 Patient neglecting the disease (C)/ increasing patients' responsibility (F)
[2.1a] Patient: Diabetes is the silent disease and that is very dangerous. (…) It doesn't hurt [laughter] and we mess up [laughter]. (FG1) [2.1b] Provider: People often don't accept they have diabetes and don't care much. [...] I mean, in type 2 diabetes people say: "Everybody has it." (FG6) [2.1c] Provider: Actually he [the patient] doesn't need very precise knowledge early on and you have to hold people accountable and provide knowledge for that and all that. (FG6)
2.2 Aggressive attitude (C/F)/positive communication approach (F)
[2.2a] Patient: "You have to do this!" With me it doesn't work, I was not used to it. (…) I get along better with the soldiers than I do with the officers. (FG5) [2.2b] Provider: I am usually not gentle. Because I get them [patients] at a stage when either we can save their leg or we have to amputate. So I just say it all and they are very shocked. (FG6) [2.2c] Provider: Maybe we should talk more about the benefits, talk more about the positive side of the therapeutic management. (FG6)
2.3 Dismissing providers responsibility (C)/investing in diabetes educators (F)
[2.3a] Provider: There has to be well trained educators ... because otherwise we are wasting trained professionals [physicians' time, knowledge] that have to do other things, right? (FG7)
2.4 Family obstruction (C)/ family support (F)
[2.4a] Provider: I ask whom cooks (…) [and] it's his wife. Then, the next day, he [the patient] comes in with his wife and she is obese, weighs 200kg. [Laughter] I mean, it's true that woman will never (…) be the driver of change. (FG6) [2.4b] Provider: 15 days ago he [the patient] went by my office and weighed 80Kg. (…) "I need to congratulate you!" (…) And I asked what happened? His daughter had entered the picture and removed the mother [his wife] from the kitchen, had started cooking and clearly squeezed the old man. (...) So, the family entered the picture. (FG6)
2.5 Patients' low health literacy/education/income (C)
[2.5a] Provider: If we don't have economic development we obviously don't have social development, we don't have more health literacy... we will always have poorer choices... (FG7) [2.5b] Provider: Oh... and I have the tendency to think this has also to do with the educational level. [...] And sometimes the person can be highly literate and have no education in terms of that specific area. (FG6) [2.5c] Provider: I have patients that see me and at first sight: "Please read this to me because I don't know how to read. I don't know how to take these medicines." (FG6) [2.5d] Provider: People don´t always have money to eat the healthier things or to buy all the drugs. (FG6)
2.6 Providing tailored practical information (F)
[2.6a] Patient: We needed to know exactly how we should and shouldn't do it [follow recommendations]. (FG3) [2.6b] Patient 1: People [patients] should also be able to change doctors anytime they don't get along with them. (FG5) Patient 2: But I don't know what is the argument and how to do it. (FG5) [2.6c] Patient: Many meetings like this one [focus group]. (...) It may not look like it, but we learn a great deal with one another. (FG2) [2.6d] Provider: We have to be very practical, very practical in what we say, very practical in the education we provide and think: "How is your day?" "It is this, this and this." Then we will work through their day with that person. (FG7) [2.6e] Provider: We sometimes tell people to walk, exercise, but you got to know the person well. If it's someone with foot pain, he or she will never walk. It's no good. (FG6)
2.7 Wake-up call (F)
[2.7a] Patient: I was supposed to take drugs for hypertension, diabetes, triglycerides, and cholesterol. (...) And I did not take them, so I ended up here [at the hospital] with a heart attack. Now, of course... after the warning, I started to take the medications, the insulin... (FG5) [2.7b] Provider: [When dealing with patients harder to motivate towards behavior change] I really think that only the wake-up call or the fact of having, for example, a brother with type 2 diabetes that had a heart attack and was at death's door. Only a family wake-up call, an emotional wake-up call makes them change. (FG6)
2.8 Macro-level interventions (F)
[2.8a] Provider: Maybe they [the fast-food and the candy] should be more expensive (…) and overtaxed. (FG6) [2.8b] Provider: I think children have a... very important role. Maybe in schools if they talked about the disease and explained [healthy behaviors]... (FG6) [2.8c] Provider: Some things [boardwalks] have contributed to that [patients having access to structures to support behavior change advice from providers]. (FG6)

Table 5. Participant quotes illustrating communication factors related with gathering and providing information

3 Gathering and providing information
3.1 Use of jargon (C)/ plain language (F)
[3.1a] Patient: Because sometimes they [providers] use words that we don't understand. (FG2) [3.1b] Provider: Then another obstacle has to do with language; sometimes there is an encrypted language, a medical language (...) that may not be easily understood by people [the patients]. (FG7) [3.1c] Patient: I wish they [the physicians] would speak small town Portuguese: "You are being treated for this, you need to do this and that!" And you learn. Now, speaking in medical terms you wonder. I do! (FG4) [3.1d] Provider: Both the family doctor and the nurse (…) know exactly what educational limitations they [their patients] have, the difficulties understanding... They [providers] adjust the language. (FG7)
3.2 Consistency between providers: lack of (C) /increased (F)
[3.2a] Patient: I tell them [providers], but it's no good. Some [the doctors] say: "eat less", [others say] "eat more during the day", [or] "add a little more insulin", "take less [insulin]". (FG4) [3.2b] Patient: I lost nine and a half kilos in a month and a half because here [at the hospital] someone incorrectly informed me of the type of diet I should be doing, right? And I almost died of starvation. (FG5) [3.2c] Provider: We had a really nice leaflet to not offend anybody just saying what was going on, just facts! The doctor didn't care, he said "It's my job to treat this!" (FG6) [3.2d] Provider: There is another important aspect, which is for the entire team to use the same language because if everybody uses the same language they reinforce each other and that gives the patient a lot of confidence. (FG7)
3.3 Providers' skills: Low competence (C)/improving communication (F)
[3.3a] Patient: I divide doctors into three classes: assembly-line doctors, doctors-just-because, and doctors-doctors. And unfortunately I get them all. (...) There's the doctor-just-because... he went through medical school and that was it. Then he forgot to study more, anyway. (FG4) [3.3b] Provider: Our own training (...) on insulins, how they work, is very limited (...) It is not something that allows me to tell patients that they need to do this and that. (FG7) [3.3c] Provider: I think there needs to be training of the professionals in ways to communicate [with patients]. (FG7)
3.4 Analogies: inappropriate (C)/ appropriate (F)
[3.4a] Patient: [Describing how another doctor explained that previous doctors had prescribed medication that caused him to feel very sick from very low blood sugar] "My colleagues did the job at 80%. Because they started giving you airplane fuel when your car should have regular fuel." (FG4) [3.4b] Patient: So, she [doctor] prescribed me the pills, all right, [but] didn't give me additional explanations... [She] told me a story that a banana is like a potato but more expensive or something [and I didn't understand what she was talking about]. (FG5)
3.5 Time: lack of (C)/ more time (F)
[3.5a] Provider: To communicate well we need first to get to know the person and even ask what he/she knows about diabetes... not assume that he/she knows just because he/she has had diabetes for a while... it's just that we don't always have the time to do it. (FG6) [3.5b] Provider: Because we categorize people by their attire, their gaze, the way they talk... and we believe the person is understanding everything but only if you take a little longer will you go the extra mile. (FG6)
3.6 Not checking for understanding (C)/ repeating information (F)
[3.6a] Provider: We want them [patients] to repeat it [what we said] but then we realize that the person didn't really listen. And what now, will we say just one [piece of information] to check if he/she listens or are we going to repeat everything one more time? No, repeating everything won't work because I don't have the time. (FG7) [3.6b] Provider: No, at that moment [the diagnosis] very little will be taken in. Moments need to be repeated. (FG7)
3.7 Unawareness of patients' needs (C)
[3.7a] Provider: What do they [patients] need to know? I have some difficulty trying to understand exactly what they need to know to change the way they act. (FG7)
3.8 Low patients' literacy/education (C)
[3.8a] Provider: Some people [the less educated] will never understand everything or... a big deal of things about the disease. (…) Some people objectively can't do it... [understand and manage medications] (FG6)

5. Conclusion

This qualitative and cross-sectional study contributes to understand how health literacy is distributed in the management of two chronic conditions – type 2 diabetes and asthma, showing that improvements in integrated care and more sustainable people-centred health systems might be achieved through an emphasis on DHL rather than just focusing on individual health literacy. Data provided by this study reveals the importance of advancing knowledge in three main areas: to explore meanings given to diagnosis; to identify health mediators and their role in patients' tasks related to health literacy; and to analyse the structure of social networks, in particular shared practices and responsibilities, and the properties of relations and ties between health mediators regarding density, range, boundedness, and homogeneity. Embracing a narrative-oriented notion of health literacy, a major strength of this thesis relies on the identification of awareness narratives, determined by the patients' response to diagnosis: (i) narrative of minimisation - patients claiming minimal impact of the chronic disease on their lives and daily routines; (ii) narrative of empathy - patients tending to follow medical recommendations without criticism; (iii) narrative of disruption - patients highlighting a huge impact of the chronic disease on their lives and their individual responsibility on illness self-management. These data reinforce the idea that people deal with information about health and illness not only on a cognitive level[192] but also by enacting a variety of needs and emotions. In addition, there is a gradient of health mediators from the disruption group to the minimization group, representing an increase of complexity as the individual health network expands, with two main consequences: disclaimer of responsibility for self-management; and inconsistent information or conflicting advice. This occurs specially within mediators with low levels of health literacy, potentially influencing the health outcomes of the patient, in line with the conclusions of other studies [44,193,194].

This study also adds important achievements to the development of integrated people-centred health services for chronic conditions, based on the cases of type 2 diabetes and asthma, in response to current calls for patients' involvement in healthcare [195,44] and governance [196]. First, it draws attention to the diagnosis as a critical starting point of the communication process of becoming a literate patient. Being diagnosed with asthma or type 2 diabetes resulted in multiple levels of engagement towards treatment, rooted in emotional factors. As other studies suggest [197-199], perspectives and experiences about diagnosis provide an important insight into how people understand and recognize disease, about ways it shapes their knowledge, self-management practices and their relation with the doctor. Jutel [199] argues the nature of diagnosis and its social significance, and how it 'explains illness, identifies treatments and predicts outcomes'. Our study identified three groups of narratives directly associated to the way patients' experienced diagnosis. Meanings given to diagnosis – minimization, empathy and disruption – were associated with a growing individual network of literacy mediators and shared practices of each patient. In some cases, it's the initial rejection of diagnosis that creates a group, as for example the narrative of disruption. In other cases, various diagnosis may establish "collective identities" (for example, having several family members or people they know with the same condition) that can (dis)empower patients and may play a role in reshaping attitudes towards the disease. The identification of narratives is innovative, and helps increase awareness on the complex nature of what is physical, mental, emotional, social and economic well-being, perceived by individuals and communities –

elements to an effective people-centred and integrated care approach. Therefore, it constitutes a step forward the involvement of the community in making policy decisions, through ownership and participation. Studies show that there is no single approach that can be applied in all contexts, and pursuing the opposite has been leading to a continuous disconnection between how people-centred and integrated care is commonly conceptualized, as WHO [200] suggests, policies and strategies need to be evidence-informed rather than evidence-based.

Furthermore, it is acknowledged that diagnosis provides recognition of what a society accepts as normal, similar to what Parsons [115] (1951) referred to as 'a claim for exemption', give meaning to symptoms and determines medical intervention [201]. The moment of diagnosis represents a two-way communication between doctor-patient: it gives structure to a narrative of dysfunction or a 'picture of disarray' [202], when the patient narrates his/her story to the doctor and, only then, once diagnosed, it is prescribed a medical label and a treatment (after of, in most of the cases, recurring to technological exams). We argue diagnosis around two different scenarios that require special attention both for doctor-patient relationships and to the health systems: diagnosis as a 'family condition' and diagnosis in childhood - the case of asthma and type 2 diabetes, respectively. Patients pointed heredity as the main cause for their chronic condition, describing type 2 diabetes as inevitable and part of family health history. Data provided by this study also suggest that these illness misconceptions are a critical point to individuals at risk of developing type 2 diabetes. Accurate information about preventive behaviours should be reassigned, mostly, to families were type 2 diabetes is prevalent and a 'family issue' [203]. The other scenario is diagnosis in the childhood. An adult diagnosed with asthma since childhood, might continue with the same medication, without reassessment for years, even if observing worsening health conditions over the time. As our study demonstrates, the treatment focuses on refill the medication, without reassessments overtime. In these cases, type of support patients needed from their doctors is instrumental and patients' expectations should be raised to the level of asthma control, that can be achieved.

These two scenarios are reflected on patients' attitudes towards the conditions, tending to minimise and avoid changing life habits. However, they have proved to beneficiate from a wide network of health mediators, that share with them disease self-management, which explains why they manage complex health conditions such as type 2 diabetes for years, without showing signs of major complications. Under the logic of an integrated people centred care, every effort should be made to encourage the organization and inclusion of health literacy mediators in medical consultations, in order to promote social equity and equality, by diminishing the chances of patients to get lost in health systems, of services fail to provide care and, at the end, to prevent not only patient but providers' satisfaction to decline.

Second, it helps in clarify the boundaries of responsibility-shifting between main health mediators, enabling effective collaboration between health professionals (in particular, family doctors and nurses), family and friends, and media (in particular, the internet and TV programs), through the identification of their roles and level of centrality in supporting management of the chronic conditions in relation to awareness narratives. The

ties established with each mediator are stronger when interactions are more frequent (intensity of ties), when it is easier to make contacts (dispersion), and when the information is comprehensible, consistent and reliable. Patients who tend to minimise diagnosis rely on a high-density network of mediators with a high number of interactions, needing for more emotional and pragmatic support from family and informational support from their doctor. By contrast, patients who enacted a disruptive narrative have a smaller and restricted group of core health mediators, mainly from formal sources of information, such as health professionals or media (internet, advice health line). The narrative of empathy only emerges in patients with type 2 diabetes, and reflects what literature describes as the 'good patient' [204], with a considerable network of health mediators needing for more emotional support from family, and putting greater emphasis on health professionals with whom they mostly rely for informational support. Close family members emerged as health mediators by providing emotional and pragmatic support, but they were not always well-succeed when giving advices[73-75]. This framework demonstrate that networks of sources of health information are wide and depend not only on the individuals capabilities to assess and rank them, but also on the perceived social identities of being asthmatic or diabetic [172].

Our study also reflects on the types or profiles of behaviors (more active or passive), and how they are influenced by the health mediators and the type of illness, giving the example of patients being avoiders or accepters [172], similar to the classification of seekers and nonseekers. Undoubtedly, the doctor is a central health mediator to all groups studied (minimisation, empathy, disruption, seekers and nonseekers) independently of the density of the networks and types of support. Indeed, and as observed in other studies [44,190,205-207], the relationships of people with their doctors are perceived as crucial and the most trustworthy medium of medical advice and health information. Trust is a major component of therapeutic relationships and patient-centred communication has been linked to doctor's communication skills [208,209]. Doctors and other health care professionals have granted positions of power and they hold authoritative knowledge, which might be relevant to consider specially in situations of power imbalance and when medical advices are contradictory [44]. As our study supports, the inconsistency between different sources of health information, e.g. providers, undoubtedly decreases the likelihood of action on that information [210].

Aiming to articulate the tapestry beyond individual patient's capabilities and responsibilities, it would be useful to create hybrid spaces for dialogue between multiple mediators in each individual networks. The DHL has proven to be typically 'situated' in such a way that to promote patient involvement and engagement in treatments and decision-making it is necessary to understand the social context of individuals and explore interactional factors, in particular patient-family doctor relationships. At the individual level, it is crucial to assist patient and family members in decision making, with health education materials, using plain language and clear communication. It is known that low health literacy can inhibit patients from actively engaging in discussions and decision making with healthcare providers and others in their networks that contribute to their care [47]. Data consistently points the need of enhancing interpersonal skills of health professionals that might contribute to the acquisition of healthcare services and social support. Improvements of community-level infrastructure, and care coordination processes, will help create an environment in which individuals use

their health literacy skills and engage with others [211]. It will also promote the adoption of evidence-informed practices [212], through improving communication skills of health professionals. Several studies have proposed clear communication and health literacy curricula for health professionals in the United States [85-87] and Europe [213]. Through exploring barriers and facilitators to communication between health professionals and patients, it became clear the importance to recognize that patients' have their own 'explanatory models of illness', i.e. personal rationalizations of the cause, course and consequences of their illness [214]. Therefore, exploring beyond the biomedical reasoning can help build empathy with patients and help them make sense of their illness experiences, leading to more effective patient-centered communication.

Finally, this study draws attention to the need to enrich support provided by formal sources of health services and peer education groups through the three following complementary initiatives. First, ongoing training communication skills and encouraging supportive communication style, to motivate patients to improve self-care, to have higher disease knowledge and better quality of life, is regarded as a crucial component of the health literacy of healthcare professionals. Commonly recognized by other studies, our study also identified the use of jargon as a barrier to effective communication. However, patients and providers had diverse perspectives concerning barriers and facilitators: interpersonal factors as barriers, such as mistrust, disrespect, inadequate response to emotions and use of inappropriate analogies were highlighted by patients; while providers dismiss their own responsibility in communication improvement, and pointed lack of time and not checking for understanding as barriers. This study also identified another contradictory perception, related to the use of an aggressive approach to communicate. Providers use it as facilitators, and literature also show some benefits in using aggressive communication with patients with limited health literacy [215], however, patients tended to see it as a barrier. This implies that providers need to make a conscious effort to tailor communication, seeing the patient as a person, and understand what best fits for him/her. An aggressive approach may even work with some patients, but with others it may have the opposite effect. To grant these sensibilities, a common tool proposed in literature is narrative medicine [95-97]. Similar to how we used narratives in our study to understand the distributed nature of health literacy of each individual, also narrative medicine is a competence claimed to be important in the clinical setting, and improve empathic and people-centred communication care – it has the ‘capacity to recognize, absorb, metabolize, interpret, and be moved by stories of illness’. Therefore, listening actively patients’ narratives, reinforcing trust, building rapport and connection, showing empathy and respecting patients’ values and decisions are some of the communication skills of the providers proposed in the literature [187].

Second, to assess the quality of health-related websites is also suggested by our results. Patients revealed difficulty to deal with the complex amount of health information, even patients who are regular internet-users. It is a fact that, if online health information offers tools of assessing information quite unconceivable a few decades ago, there is still improvements to make in order to achieve the potential described in literature [188].

And third, to promote education groups with peers and family members. Previous studies show that education support groups provide emotional, social, and practical assistance to patients to help manage their illness [189].

In spite of education groups with peers and family been widely proved as beneficial, especially for people who live with chronic conditions, by motivating and engaging with daily management [190], literature shows that there are barriers to peer support groups. These barriers are more evident when health systems do not recognize peer support, and may include the lack of training, lack of support, lack of supervision, monitoring and evaluation of peers [189]. A key strategy proposed is to tailor treatment as closely as possible to patients' needs, an approach that takes into account patients' DHL - understanding of illness, social networks, levels of influence, types of support and ways to optimize their potential.

These achievements may allow a deeper understanding of the complexity of individual circumstances and the reasoning behind their health decisions and actions [191], by showing how the involvement of multiple mediators in each individual networks contributes to different health literacy practices. It is then necessary to clarify boundaries of responsibility-shifting between health mediators and patients through two main viewpoints: firstly, identifying networks and types of support, and secondly, exploring interactional actors to understand patients' attitudes whether towards asthma or type 2 diabetes. However, future work is needed to assess how networks configurations change over time and how types of support are affected through life-course.

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Appendices

APPENDIX 1. Study Information Sheet

contribua para uma melhoria da comunicação entre os serviços de saúde e os doentes.

Sou obrigado a participar?

Não. Caso decida não participar, esta decisão não terá qualquer influência em nenhum dos serviços de que usufrui. Mesmo depois de aceitar, poderá, em qualquer altura e sem justificação, desistir.

Como será usada a investigação?

Os resultados deste estudo serão divulgados junto de várias pessoas, incluindo os profissionais que trabalham nestas áreas e aqueles que podem tomar decisões em relação à melhoria dos serviços prestados.

Obrigado por ter lido este folheto!

A sua participação será muito valiosa.

A entrevista apenas prosseguirá depois de colocadas todas as questões pelo participante e após assinatura do consentimento informado.

Ser-lhe-á dado este folheto informativo e uma cópia do consentimento informado.

Contato Investigadora Responsável:
Liliana Abreu – 22 040 8800
E-mail – Liliana.abreu@ibmc.up.pt

Este trabalho é financiado pela FCT – Fundação para a Ciência e a Tecnologia no âmbito do projeto ref. SFRH/BD/78949/2011

U.PORTO
FMUP FACULDADE DE MEDICINA UNIVERSIDADE DO PORTO

Estudo sobre literacia em saúde distribuída de pessoas com diabetes

contribua para uma melhoria da comunicação entre os serviços de saúde e os doentes.

Sou obrigado a participar?

Não. Caso decida não participar, esta decisão não terá qualquer influência em nenhum dos serviços de que usufrui. Mesmo depois de aceitar, poderá, em qualquer altura e sem justificação, desistir.

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U.PORTO

FMUP FACULDADE DE MEDICINA UNIVERSIDADE DO PORTO

Estudo sobre literacia em saúde distribuída de pessoas com asma

Folha de informação
sobre o estudo

Bom dia!

Está a ser desenvolvido um estudo com pessoas com asma sobre o conhecimento que têm acerca da doença e a forma como fazem a gestão da doença no seu dia a dia.
Gostaríamos de contar com a sua participação.

Antes de decidir se quer participar, é importante que saiba mais acerca deste estudo e do que lhe é pedido se aceitar participar.

Por favor leia atentamente este folheto informativo e coloque todas as perguntas que achar necessário.

Obrigado pelo tempo concedido à leitura desta informação!

Por que queremos falar consigo?

A finalidade deste estudo é conhecer a as experiências das pessoas que vivem com a asma, com particular atenção nas necessidades de informação e na partilha de conhecimento.

Serão convidados a participar neste estudo pessoas diagnosticadas com asma.

Entre outros aspectos, a informação recolhida será útil para:

- Melhorar a comunicação com os profissionais de saúde;
- Conhecer as necessidades de informação dos doentes;
- Compreender o conhecimento de cada um sobre os tratamentos e cuidados recomendados;
- Perceber a importância atribuída à partilha da gestão da asma com familiares mais próximos.

Quem é responsável pelo estudo?

O estudo é financiado pela **Fundação para a Ciência e a Tecnologia** e está a ser executado no âmbito de um projeto de investigação do Programa Doutoral em Saúde Pública da Faculdade de Medicina da Universidade do Porto.

O que é que este estudo envolve?

Gostaríamos que participasse numa entrevista individual.

No total, terá uma duração máxima de 60 minutos. A entrevista incidirá sobre a sua experiência com a asma desde o momento do diagnóstico.

Durante a entrevista, pode colocar todas as dúvidas e questões que deseje.

Como participante não terá que falar sobre assuntos que prefira não abordar.

A pesquisa é confidencial?

Sim. Toda a informação que partilhar connosco será vista somente pelos membros da equipa de investigação.

A informação será armazenada de forma segura. Isto significa que, sempre que se utilizar alguma informação mencionada na entrevista, nunca será usado o seu verdadeiro nome.

Quais serão os benefícios da minha participação?

Apesar de não receber um benefício direto por participar neste estudo algumas pessoas têm uma experiência positiva ao partilhar a sua história. Esperamos também que este estudo contribua para ajudar os doentes na gestão diária da doença, através de um mapeamento das necessidades de informação e, também, que contribua para uma melhoria da comunicação entre os serviços de saúde e os doentes.

APPENDIX 2. Informed Consent

CONSENTIMENTO INFORMADO, LIVRE E ESCLARECIDO PARA PARTICIPAÇÃO EM INVESTIGAÇÃO

de acordo com a Declaração de Helsínquia e a Convenção de Oviedo

Por favor, leia com atenção a seguinte informação. Se achar que algo está incorrecto ou que não está claro, não hesite em solicitar mais informações. Se concorda com a proposta que lhe foi feita, queira assinar este documento.

Título do estudo: Literacia em saúde distribuída na asma e diabetes

Enquadramento: Este estudo está a ser desenvolvido no âmbito de um projeto de doutoramento em Saúde Pública da Faculdade de Medicina da Universidade do Porto, sob a orientação científica do Professor João Arriscado Nunes.

Explicação do estudo: Este estudo implica a participação voluntária de doentes, com asma ou diabetes, numa única entrevista individual, gravada em áudio, onde lhe serão colocadas questões relacionadas com gestão da doença, o seu conhecimento e o impacto que a mesma tem no seu dia a dia. A entrevista durará aproximadamente uma hora e será realizada no seu Centro de Saúde. O investigador destruirá as gravações e os ficheiros após publicação dos resultados.

Confidencialidade e anonimato: Planeamos publicar os resultados deste estudo, mas não incluiremos nenhuma informação que o identifique. Para proteger a sua privacidade, a gravação da entrevista será guardada e unicamente acedida pelo investigador até uma transcrição palavra por palavra ter sido criada. Os investigadores introduzirão os dados num computador protegido por palavra-passe e que utiliza codificação especial para proteger a informação. Para proteger a confidencialidade, o seu nome não será usado na cópia escrita da discussão.

Natureza voluntária do estudo: Participar no estudo é totalmente voluntário. Mesmo que decida participar agora, pode mudar de ideias e deixar de participar em qualquer altura. Pode decidir não responder a uma questão da entrevista por qualquer razão.

Informação de contato: Se tiver questões sobre este estudo, incluindo questões sobre o agendamento ou localização da entrevista, poderá contactar a investigadora principal do projeto:

Liliana Abreu
Telefone: **226074900** (extensão **1006**)
e-mail: **liliana.abreu@ibmc.up.pt**
morada: **Instituto de Biologia Molecular e Celular da Universidade do Porto**
Rua do Campo Alegre, 823, 4150-180 Porto

Assinatura/s: … … …

APPENDIX 3. Qualitative interview guide

McGill Illness Narrative Interview (MINI) - *adaptado*[1]

Parte 1. Narrativa exploratória

1. Quando é que sentiu os primeiros sintomas da sua doença?
   (Deixar o entrevistado desenvolver o máximo esta questão. Apenas ir perguntando "E o que aconteceu a seguir?" "E depois?")

2. Gostaríamos de saber mais sobre a sua experiência. Pode contar-nos sobre o momento em que descobriu que sofria desta doença?

3. Pode contar-nos o que aconteceu no momento em que surgiu a doença? (e o que aconteceu depois)

4. Aconteceu mais alguma coisa?

5. Caso tenha consultado um médico, conte-nos como foi a consulta e o que o que sucedeu a seguir.

   5.1. Fez alguns exames ou tratamentos relacionados com a sua doença? Que tipo de exames?
   5.2. Actualmente faz algum tratamento?
   5.3. Já alguma vez foi internado(a) por causa da sua doença?

6. Procurou algum outro tipo de ajuda ou tratamento? (medicinas alternativas…). Conte-nos como foi essa experiência e o que aconteceu de seguida.

Parte 2. Narrativa protótipo

7. No passado, alguma vez teve um problema de saúde que considere semelhante ao que tem?

8. Em que medida é que esse problema do passado é semelhante à sua doença?

9. Teve ou tem algum familiar com um problema semelhante ao seu?

10. Em que medida acha o seu caso semelhante ou diferente do seu familiar?

11. Algum conhecido seu (amigo pessoal ou colega de trabalho) teve algum problema semelhante ao seu?

12. Em que medida considera a sua doença diferente ou semelhante à doença dessa outra pessoa?

13. Alguma vez viu, leu ou ouviu na televisão, rádio, jornais, livros ou na Internet alguém que tenha a mesma doença?

[1] As questões em itálico foram as questões adaptadas para este estudo e adicionadas à versão original do MINI.

14. Em que medida é que acha que o problema dessa pessoa é similar ou diferente do seu?

Parte 3. Modelo da narrativa explicativa

15. Que conhecimentos tem sobre Asma/Diabetes?

16. Na sua opinião, o que é que acha que causou a sua doença? (Causas principais)

    16.1. Acha que existem outras razões, para além das que referiu, que também possam ter contribuído para o aparecimento da doença? (Causas secundárias)

17. O que acha que aconteceu para a doença ter despoletado naquele momento específico da sua vida?

18. Aconteceu algo na sua família, no trabalho ou na sua vida pessoal que possa explicar a sua doença?

19. Pode contar-nos como é que isso explica o seu problema de saúde?

20. O que é que Asma/Diabetes significa para si?

21. O que é que acha que geralmente acontece às pessoas que têm Asma/Diabetes?

22. Qual é o melhor modo de lidar com as pessoas que têm Asma/Diabetes?

23. Como é que as outras pessoas reagem a alguém que tenha Asma/Diabetes?

24. Conhece alguém que tenha tido asma?

25. Em que medida é que a sua doença é semelhante ou diferente do problema de saúde dessa outra pessoa?

26. Acha que a sua doença está de algum modo relacionada com alguns acontecimentos específicos da sua vida?

27. Pode falar-nos mais sobre esses acontecimentos e de que forma estão ligados à sua doença?

Parte 4. Serviços Médicos e Respostas ao Tratamento

28. Durante a sua visita ao médico que problema ele lhe disse que tinha?
    28.1. Como lhe foi dada essa informação?
    28.2. Como é que recebeu essa informação?

29. O seu médico receitou-lhe algum tratamento, medicamentos ou deu-lhe algumas indicações a seguir? Enumere todas.
    29.1. Como é que está a lidar (ou lidou) com essas indicações?
    29.2. Sente-se capaz de seguir o tratamento (Ou indicações ou medicamentos)?

30. O que é que acha que funcionou bem no tratamento?

31. O que é que não funcionou bem, e o tornou difícil de seguir?

32. Tem alguém que o ajude a gerir a medicação e outras recomendações médicas?

33. Costuma ir acompanhado às consultas? Se sim, por quem?

34. Relativamente à sua doença, que tratamentos esperava receber e não recebeu?
    34.1. Que outra terapia, tratamento, ajuda ou cuidado, procurou, mas não encontrou?
    34.2. Que outra terapia, tratamento, ajuda ou cuidado gostaria de receber?

Parte 5. Impacto na vida

35. A doença mudou o seu modo de vida? Como?

36. A doença mudou a forma como se vê a si próprio? Como?

37. A doença mudou a forma como vê a vida? Como?

38. A doença mudou a forma como os outros o veem? Como?

39. Se lhe pedíssemos para escolher pelo menos uma pessoa para o ajudar em algum assunto relacionado com a sua saúde, quem escolheria? (deixar claro que pode escolher mais do que uma pessoa)

40. O que é que o ajudou a atravessar este período da sua vida?
    40.1. Teve a ajuda da família ou de amigos para ultrapassar este período da sua vida? Como?
    40.2. A sua vida espiritual, fé ou prática religiosa ajuda-o a ultrapassar este período da sua vida?

Parte 6. Fontes de informação e suporte social

41. Procurou obter informação sobre a sua doença, após o diagnóstico? (questionar o papel do médico, e de seguida, outras fontes: Internet, jornais, televisão, rádio)
    41.1. Onde procurou essa informação?
    41.2. A informação que obteve contribuiu para conhecer melhor a doença? Como?
    41.3. A informação ajudou-o a lidar melhor com a doença e os tratamentos? Como?

42. Que informação acha que um doente deve receber quando lhe é comunicado o diagnóstico?
    42.1. Quem lhe deve transmitir essa informação?

43. O que é que acha que dá credibilidade à informação que recebe/encontra? (hierarquia de credibilidade)

43.1. *Se visse a assinatura de médico num certo conteúdo, daria maior credibilidade a essa informação?*
43.2. *Quais as fontes de informação que considera mais importantes?*
43.3. *Costuma conversar sobre assuntos de saúde com familiares, amigos ou colegas? (ou outros grupos...)*

44. *Usa frequentemente a internet para procurar informação sobre saúde? Se sim, quais os factores que mais influenciam a escolha de uma determinada página?*
    44.1. *Na sua opinião, a qualidade da informação sobre saúde na Internet é geralmente boa?*

45. *O que deveria ser feito para melhorar a comunicação entre profissionais de saúde e pessoas com diabetes/asma?*

46. *Há algo mais que queira acrescentar?*

Podemos dar por terminada a entrevista. Muito obrigada pela sua disponibilidade.